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ABSTRACT

This paper presents annual findings of follow-up work with mentally retarded school completers begun in 1987. Information was gathered on each youth's current living and work situations, as well as job and training involvement throughout the year. Findings indicated widespread stability in the group, but little progress toward achieving real work goals. Most subjects were living with their parents/guardians. Competitive employment proved viable for many subjects, while supported work initiatives seemed to have had little effect in the area. Issues and service needs pertaining to these findings are also discussed. Contains 30 references. (PB)

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THREE YEARS OF FOLLOW-UP OF MENTALLY RETARDED YOUTH: STABILITY AND CHANGE

by

Elizabeth Gordon, Ph.D.
Robert L. Goldbach

COMMUNITY RESEARCH ASSOCIATES

consultants to

HEALTH AND WELFARE PLANNING ASSOCIATION
200 Ross Street
Pittsburgh, PA 15219

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Three Years of Follow-up of Mentally Retarded School Completers: Stability and Change

EXECUTIVE SUMMARY

This year's work expands the follow-up of mentally retarded school completers begun in 1987 and continued in 1988. Parents and guardians of youngsters who completed their educations in the Allegheny Intermediate Unit's special educations programs in 1985-1986 and 1986-1987 were contacted. This is the third year of follow-up for the 1985-1986 group and the second year of follow-up for the 1986-1987 group. As in previous years, information was gathered on youngster's present living and work situations, and job and training involvement over the year. A considerable number of new areas were also explored this year. This report presents a review of study findings, a discussion of stability and change in the sample and in the service system, and conclusions, issues and service needs deriving from the study process. Study findings are also presented, in both a summarized version and in detail.

CONCLUSIONS, ISSUES AND SERVICE NEEDS

Conclusion I: The situation of the study sample, in terms of living arrangement and work situation, is one of great stability and small changes. Also, the group as a whole did not make significant progress toward achieving real work goals over the year.

Issue: Plans made for youngster's first year after school is completed are critical. Especially for more disabled individuals, few changes in residential and vocational situations occur after initial placements are made.

Service needs: Transition planning for youngsters to help bridge the gap between school and work begun early in youngsters' high school careers. Post-school training and job placement options carefully chosen to utilize youngsters' full potential. Placements periodically reviewed.

Conclusion II: The majority of mentally retarded school completers are firmly ensconced in their parents'/guardians' homes. A large percent of youngsters live with their parents and guardians after completing school, and parents are quite satisfied with this arrangement.

Issue: Whether an enthusiastic choice, or one made by default, the majority of youngsters will remain at home with their parents and guardians for the foreseeable future.

Service needs: Support services for families caring for

retarded youngsters at home, increased availability of places in acceptable CLAs for those parents who prefer it or can no longer care for their youngster, development of viable residential alternatives for youngsters for when parents become unable to provide care.

Conclusion III: Competitive employment has proven a viable option for a considerable portion of the sample, especially EMRs.

Issue: Competitive employment appears to offer the greatest potential for mentally retarded youngsters, in terms of use of their abilities, financial independence and entrance into the mainstream of society.

Service needs: Continued in-school cooperative education, expansion of post-school vocational programming, increase in the number of youngsters receiving training in fields with a future.

Conclusion IV: The work-related situations of most of the sample are not congruent with the latest thinking in terms of the vocational potential of the mentally retarded. There is little evidence in the present study that supported work initiatives have affected local school completers.

Service needs: Working with parents to explore additional vocational options for their youngsters, making more places available in supported work programs, moving people presently in WACs and workshops to more ambitious vocational options, and placing individuals directly from school into supported work.

STUDY FINDINGS

Living arrangement: The sample still lives largely with parents or guardians, and there has been only very slight movement, for some EMRs, to more independent living situations over the year. The great majority of parents and guardians are satisfied with that arrangement. Many had positive comments which indicated that they like the arrangement or felt it was best for their youngster. Some had negative comments that indicated that living at home was not good for the youngster and was difficult for them. Most parents appear to view this situation as largely permanent: most do not anticipate any change in youngster's living arrangement over the next five years, and have never explored the possibility of the youngster living away from home. The major circumstances that would lead parents to consider their youngsters living away from home is their own infirmity or death. In those circumstances, most feel their youngster would go to live with a sibling or to a CLA. There appears to be great variation in the frequency of social interaction of youngsters living at home. 49% sees friends at least once a week. However, 26% never interact with friends and another 11% only once a month or less.

Work situation: About 1/3 of the sample is in competitive employment, almost all of them EMR. The sample has, as a whole, not realized any more jobs over the year. Significant subgroups are in activity centers (20%) and sheltered workshops (15%), and most of these individuals have been in these placements since they left school. A few have moved into sheltered workshops this year. The TMRs seem to be largely subsumed in the activities center option. A considerable subgroup of the sample is idle and most are part of a group of hard-core unemployed who have been idle at every follow-up interview. These individuals are seen by their parents as not working largely because they cannot handle work situations because of their disability.

Competitive employment: A little over a quarter of the youngsters in the sample are employed, mostly in competitive work. Two are in supported work situations. The great majority of employed are EMR. About 1/3 of those holding jobs are employed in restaurants and fast food outlets; 23% are working in hospitals and nursing homes. 6 out of the 10 working in the health care sector have obtained their jobs in the last year, indicating that this may be a growing employment sector for the mentally retarded. Jobs held by workers in our sample include janitor, nurse's aide, dishwasher, laborer, busboy, and other restaurant positions. The workers work an average of 31.9 hours a week and earn an average of $4.12 an hour. Their average weekly salary is $137.97. 60% of the workers holding the same jobs since last year have received increases in their hourly wage and/or weekly hours.

Training and placement: 17 youngsters have completed vocational training programs since leaving school. The most popular training programs were Nurse's Aide, Janitor/Custodian and Food Service. 14 of the 17 trainees (82%) obtained a job after completion of their training; 10 of these in the fields in which they were trained. Center EMRs and SED/LAPs who received post-school vocational training were significantly more likely to be employed than those who did not receive such training.

Parent concerns and desired help from human services: Work and vocational training is the most frequently voiced concern of parents, and the area in which they would most like help from the human service system. The next most frequently cited concerns were their own infirmity or death and the physical health of their youngster. Additional concerns include: housing, social skills, financial self-sufficiency, and generally coping with life. Only a few additional types of social service help were desired by parents. The second most frequently requested area of social service assistance was social and recreational programs for youngsters. Third was additional education in basic life areas. Additional help desired by particular parent groups include respite care (SPMR and TMR) and housing opportunities and residential facilities (SPMR and PH/SED). 22% of the sample wants no help from the human services system.

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INTRODUCTION

The 1989 HWPA/CRA project underwritten by the Edith L. Trees Charitable Trust has allowed us to obtain a long-range, longitudinal view of mentally retarded school completers. We had, in past years, studied mentally retarded youth as they were leaving school. In 1987, we followed youngsters who had completed their educations in 1985-1986 at the special education centers administered by the Allegheny Intermediate Unit (AIU). In 1988, we continued to study this 1986 cohort, and also began follow-up of the next year's group of youngsters, those who had completed school in 1986-1987. This 1987 group not only included those who had studied at the special education centers, but also a group of mentally retarded youngsters who had been mainstreamed at area high schools in classrooms under the auspices of the AIU. In continuing our follow-up of these two cohorts of young people this year, then, we have studied our initial group for the third year since they have left school, and our second group, for its second post-school year. What begins to emerge is a picture of these young people as their lives begin to assume their adult dimensions.

In speaking to parents and guardians of mentally retarded youngsters for the second and third year in a row, we have come to know them and their families, and they have come to know us. Many have grown to expect our yearly call, and wait to tell us how their youngster has done over the past year. The people in our sample have come to be more than names to us, they are individuals whose histories and circumstances are familiar. Although keeping our perspective as researchers, we can't help but be gladdened to hear of triumphs; of youngsters who have found meaningful work that they are able to continue year after year, or who have overcome drug or alcohol problems and found jobs. We are saddened by setbacks; by a youngster whose achievement in maintaining a supported work position is ended when a less sympathetic store manager forces her out, or by those whose parents are beset by worry as they see them regressing with each year at home. We have spent long periods on the phone learning what it is like to live with a severely retarded son, from a father who wants us to understand his situation and who extends an invitation to really learn what its like by spending a week in the family home. We have come to appreciate the impact on the family of a youngster with psychiatric problems along with retardation; the difficulties of finding a suitable placement and gaining acceptance by other family members. We have followed youngsters from year to year as they change positions and residences, tracking them down through parents and siblings, only to lose them when the phone number of the last available contact

is disconnected. We wonder what happened to them and where they wound up; if their continued movement is a good or bad sign.

In the years of our study, these youngsters have moved from being high school students to young people in adult society. The subjects of our research now range in age from 18 to 26; most are 23 to 25 years old this year. Our study has charted their move from school - which incorporated a structured system of services designed to meet many of their recreational, educational and social needs - to adult society, which incorporates no such mandated system of services. Families and individuals have had to seek their own solutions to meeting the varied needs of their mentally retarded offspring, and have done so with markedly different degrees of success.

This year's report, then, will attempt to communicate what we have learned in our three years of follow-up of these youngsters and their families. In the report, we will be looking at the basic life conditions of housing and work, as well as exploring job and training involvement over the year. We will also cover items explored for the first time this year. A number of these arose out of our consistent finding that a large percent of our sample lived at home with parents or guardians. We wanted to investigate this further and developed questions which explored such areas as respondents' satisfaction with living situation, plans for the future, and exploration of housing alternatives. Parents were also asked their major concerns for their younsters' lives and future, and the areas in which they desired help from human services.

The following report presents a review of study findings, a discussion of stability and change in the sample and in the service system, and conclusions, issues and service needs deriving from the study process. Study findings are also presented, in two study sections. Study Section I is a summary of the findings; Study Section II presents the methodology of the study and detailed findings.

REVIEW OF FINDINGS

Review of findings: This section will present the major trends seen for our study sample.

Living arrangement: The sample still lives largely with parents or guardians, and there has been only very slight movement, for some EMRs, to more independent living situations over the year. The great majority of parents and guardians are satisfied with their youngster living at home. Many had positive comments which indicated that they like the arrangement or felt it was best for their youngster. Some had negative comments that indicated that residing at home was not good for the youngster and was difficult for them. Most parents appear to view this situation as largely permanent: 63% do not anticipate any change in youngster's living arrangement over the next five years, and the same percent have never explored the possibility of the youngster living away from home. The major circumstances that would lead the parents (50%) to consider their youngsters living away from home is their own infirmity or death. In those circumstances, most feel their youngster would go to live with a sibling (42%) or to a CLA (36%). There appears to be great variation in the frequency of social interaction of youngsters living at home. 49% see friends at least once a week. However, 26% never interact with friends and another 11% only once a month or less.

Work situation: About 1/3 of the sample is in competitive employment, almost all of them EMR and the sample has, as a whole, not realized any more jobs over the year. Significant subgroups are in activity centers (20%) and sheltered workshops (15%), and most of these individuals have been in these placements since they left school. A few have moved into sheltered workshops this year. The TMRs seem to be largely subsumed in the activities center option. A considerable subgroup of the sample is idle and most belong to a hard-core group of unemployed who have been so at every follow-up interview. These individuals are seen by their parents as not working largely because they cannot handle the work situation, their disability prevents work or their skills or ability is not sufficient for work and second, because of their negative attitude. Some of those unemployed have not been able to find work or have never pursued this option. Those idle individuals who have held jobs in the past are seen, most commonly, as not being able to handle the work, being dissatisfied with an aspect of work, being dismissed from their jobs or having a job or program end.

Competitive employment: A little over a quarter of the youngsters in the sample are employed, mostly in competitive

work. Two are in supported work situations. The great majority of employed are EMR. About 1/3 of those holding jobs are employed in restaurants and fast food outlets; 23% are working in hospitals and nursing homes. 6 out of the 10 working in the health care sector have obtained their jobs in the last year, indicating that this may be a growing employment sector for the mentally retarded. Jobs held by workers in our sample include janitor, nurse's aide, dishwasher, laborer, busboy, and other restaurant positions. The employed individuals work an average of 31.9 hours a week and earn an average of $4.12 an hour. They earn an average of $137.97 a week. 60% of the workers holding the same jobs since last year have received an increase in their hourly wage and/or weekly hours.

Training and placement: 17 youngsters have completed vocational training programs since leaving school. 71% of these youngsters were center completers, 29% mainstreamed. The most popular training programs were Nurse's Aide, Janitor/Custodian and Food Service. 14 of the 17 trainees (82%) obtained a job after completion of their training; 10 of these in the fields in which they were trained. Vocational training appears to have been important for center completers. Center EMRs and SED/LAPs who received post-school vocational training were significantly more likely to be employed than those who did not receive such training.

Parent concerns and desired help from human services: Work and vocational training is the most frequently voiced concern of parents, and the area in which they would most like help from the human service system. The next most frequently cited concern was their own infirmity or death. Physical health of their youngster was the third most frequently cited concern. Additional concerns voiced by parents include: housing, social skills, financial self-sufficiency, and generally coping with life. Only a few additional types of social service help were desired by considerable numbers of parents. The second most frequently requested area of social service assistance was social and recreational programs for youngsters. Third was additional education in basic life areas. Additional help desired by particular parent groups include respite care (SPMR and TMR) and housing opportunities and residential facilities (SPMR and PH/SED). 22% of the sample wants no help from the human services system.

DISCUSSION: STABILITY AND CHANGE

The Sample

The major finding of the study in terms of the major life areas of living situation and work situation is great stability and slight change. Looking individually at the three major exceptionality groups in the sample in these terms, we find:

SPMR: All individuals have been in the same living and activity situations since leaving school. No change in either living arrangement or activity situation is seen for any SPMR individual in the course of the study.

TMR: The TMR individuals also show great stability in living arrangement and work-related situation. 85% of the total TMR sample (41/48 individuals) have been in the same living and work situations since leaving school. 80% of the '86 cohort and 91% of the '87 cohort exhibit this stability in living and work situations. Only 7 TMR individuals (15% of TMR sample) - 5 from the '86 cohort and 2 from the '87 cohort - have had any change in living or work arrangement in the course of the study.

EMR: The EMR exceptionality is the only one showing some degree of change in living and work arrangement. 43% (32/75) of the total EMR sample has experienced a change in living arrangement and/or work situation over the course of the study. The majority of EMR individuals (57%, 43/75 persons) have also been in the same living arrangement and work-related situation since leaving school. Breaking this down by cohort means that 52% (12/23) of the '86 center cohort, 63% (17/27) of the '87 center cohort, and 56% (14/25) of the mainstream cohort have been stable in respect to these variables.

In considering what this situation of great stability and some change means in terms of the development of our sample in the years we have been following it, a number of aspects can be considered. First, the specific changes that were seen and second, the individuals lost to follow-up.

Changes in the situation of the sample from 1988-1989: Let us first look at the changes that have occurred for our study sample over this year, to determine what occurred for the sample as a whole:

Changes in Living Arrangement 1988-1989

	#	1988		1989
Center EMR	2	Parent/guardian	------>	Independent
	2	Parent/guardian	------>	CLA
	1	Independent	------>	Parent/guardian
Mainstream	2	Parent/guardian	------>	Independent
	1	Parent/guardian	------>	Aunt
TMR	1	Parent/guardian	------>	CLA
	2	Parent/guardian	------>	Institution

Net changes for the sample as a whole: 3 individuals moved from parent/guardians to independent living situations; 3 from parent/guardians to CLAs; 1 from parent/guardians to aunt; 2 from parent/guardians to institutions.

Changes in Work Situation 1988-1989

	#	1988		1989
Center EMR	1	Sheltered workshop	---->	Activities Center
	1	Activities center	---->	Sheltered Workshop
	2	Idle	---------->	Sheltered Workshop
	1	Idle	---------->	Compet. Employment
	1	Compet. Employment	---->	Idle
Mainstream	1	Idle	---------->	Sheltered Workshop
	4	Idle	---------->	Compet. Employment
	4	Compet. Employment	---->	Idle
TMR	1	Idle	---------->	Sheltered Workshop
	1	Activities center	---->	Training

Net changes for the sample: No gains in competitive employment (entries = exits). 4 individuals went from idle to sheltered workshop.

The direction of the changes seen: Looking at these findings, we can begin to understand the direction of the changes in major life areas. Again, SPMRs have had no change in either living arrangement or work. There have been a small number of changes for TMRs. The one TMR individual who moved to a CLA might be regarded as having moved to a more independent living arrangement (although that depends on the CLA). The 2 moving to residential institutions have moved to less independent situations. Changes in work situation for the TMR group, both

the move from idle to sheltered workshop, and the one from activities center to training, may be seen as progressive. The changes for EMRs appear to be generally in the direction of increased independence, with 4 individuals moving from parent/guardians to independent living situations, and 2 moving from parent/guardians to CLAs. Countering that trend is the move from independent living situation back to parent/guardians. The net change in work situation of the EMRs, involved 3 individuals moving from idle to sheltered workshop. In terms of the group as a whole, the other noted changes cancel out each other. This might be seen as a slight advance for this group, although the current philosophy of vocational placement for the mentally retarded would be likely to regard sheltered workshop placement for EMRs as less than optimal.

In sum, has the sample as a whole shown progress in terms of movement to more independent living and work situations from 1988 to 1989?:

SPMRs: no changes.

TMRs: no progress in terms of living arrangement; very slight advances, involving 2 individuals, in work situation.

EMR: slight moves towards more independent living arrangements; very slight moves in terms of work, involving only sheltered workshop placements.

Individuals lost to the sample 1988-1989: In understanding the implications of the finding of great stability and small change in major life areas, we must consider the individuals lost to the sample between the two years. Is the lack of change seen due to the loss of those who have experienced changes in situation, leaving a sample comprised of a more stable core?

The chart on the next page outlines the characteristics of those lost to follow-up from 1988 to 1989. The first observation is that it is likely that those lost did move around more than those who remained, as 89% of losses were due to telephone disconnections and wrong numbers, indicating changes of residence. Whether this indicates changes in *type* of living arrangement, however is questionable. 17 out of 19 lost to the sample (89%) were living with parent or guardian in 1988, a percent higher than the sample in 1988 or in 1989. Telephone disconnections and wrong numbers indicate that *the entire family* left the previous residence. The most likely scenario is that youngsters lost to follow-up moved with their parents/guardians to a different residence. It is unlikely that a considerable number moved to other types of living arrangements. Of course, this is not possible to determine with certainty and we may have lost some individuals whose living arrangements changed over the

year. However, the magnitude of those changes, if they did occur, are not unlikely to have been large enough to challenge the veracity of our findings.

We can also speculate in terms of the work situations of individuals lost to the sample and how they impact on the findings. Among youth lost those lost to the sample, the percentages of both those working (42%) and idle (47%) is higher than that of the remaining sample. The percents in activities centers (11%) and sheltered workshops (5%) is lower. We can speculate on the nature of changes in work situations that may have occurred for the group lost to follow-up. Activity center and sheltered workshop participants tend to remain in those placements, and so these individuals are unlikely to have had changes. Changes may have occurred in the number of those working and idle. In the case of our 1989 sample, the changes in each of these cancelled out each other in terms of the sample as a whole, leaving no net change: as many individual went from work to idle as from idle to work. We don't have any reason to suppose that there were great changes in a particular direction among those lost to follow-up. Among those lost to the sample, the number of working (8) and idle (9) in 1988 was very similar. It is, therefore not likely that big changes in a particular direction occurred in the work situations of this group, but rather, that a few workers became idle and a few idle began to work in the past year. The net change is not likely to have been very great. Although we can't be totally certain of this, we can remain fairly comfortable that it is not the loss of particular individuals that brought about the great stability and slight change in both living arrangement and work situation that we see for our sample, but rather, that this reflects the life situation of our MR school completers.

INDIVIDUALS LOST TO SAMPLE FROM 1988 TO 1989

	TMR	EMR 1986	EMR 1987	Main-stream	SED 1986	Total	(%)
Living Arrangements							
Parent/Guardian	3	3	6	4		16	(84)
Foster Home			1			1	(5)
With Spouse					1	1	(5)
Alone				1		1	(5)
Work Situation							
Idle	1	1	4	2	1	9	(47)
TAC	1					1	(5)
WAC		1				1	(5)
Sheltered Workshop	1					1	(5)
Competitive Employment		1	3	3		7	(37)
Sex							
Male	1	2	4	1		8	(42)
Female	2	1	3	4	1	11	(58)
						19	(100)

The Service System

Retrenchment: There is a change apparent that will have a major impact on our study subjects and others like them. A retrenchment policy that will have far-reaching effects on the services the mentally retarded and their families receive has begun in Allegheny County. Inadequacy of state funding has meant a "retrenchment and redirection" of the County's Mental Health/Mental Retardation Program. (Peters, 1989) The director of the program has told local agencies providing services that they can close admission to their programs in anticipation of cutbacks in July. Non-residential programs - day activities, counseling, vocational rehabilitation - will experience the greatest cuts. Within this fiscal year, until July, there will be no expansion of services, increase of staff salaries or reduction of the substantial waiting lists for all services. Starting in July, unless the state provides money for mentally retarded people who live at home, a reduction in services is

likely with programs being shut down or cut back and clients being discharged. Presently, programs are being reduced by attrition, with no replacement of individuals who leave. The executive director of Allegheny East, a subcontractor to the county which provides services to the mentally retarded in the eastern suburbs, plans to stop maintaining a waiting list, feeling that having such a list is misleading and unethical indicating falsely to parents that their needs are being understood. (Blazina, 6/25/89)

Present waiting lists for services are considerable enough that the thought of cuts gives one pause. As indicated by the County MH/MR/D&A (Firth and Schwartzman, 1989), the present waiting list for vocational rehabilitation, which includes supported employment, WACs, and sheltered workshops, is 270, and involves a 2 year wait. The waiting list for TACs is 92, with a wait of over two years. 317 mentally retarded individuals are on the waiting list for CLAs, and an additional 177 are on an emergency CLA placement list. Both involve years of waiting before a place becomes available. The budget for family support services, which involves only minimal services per family at present, is to be cut 5%.

The impact of the retrenchment on the mentally retarded and their families probably cannot be overestimated. Those youngsters who are in no programming at present are unlikely to find a placement. Whether parents are interested in CLA placement for their youngsters becomes a moot point, as that possibility recedes into the distance. Charles Peters, the director of Allegheny County's MH/MR, told a recent meeting of heads of agencies and organizations that serve the county's mentally retarded, "We're delusioning the population that we're serving them. There is not enough money for quality services. The system is bankrupt."

The implications for the population of young people like those in our sample are clear. We have seen that they primarily live with their families and that their families depend a great deal on vocational programming such as vocational training programs, activity centers and sheltered workshops. At the present level of service provision, there are many youngsters not served by the system - waiting for program openings, falling in the cracks in terms of eligibility, having special needs for which no services are apparent. Many of these families, especially those whose youngster is severely impaired, are just barely managing to cope given present levels. Some hang on, hoping for a program opening, clinging to the knowledge that they are on a waiting list, however long. The present retrenchment is likely to leave such families in desperate straits, with those waiting for programs increasingly unlikely to ever be served, and some youngsters eventually released from their current programming. The effects are likely to fall especially heavily

on the more severely retarded and their families. We have seen that it is the families of SPMRs and TMRs who consider CLAs for their youngsters. (Those with EMRs tend to aspire to independent housing arrangements.) These groups are also more dependent on TAC and WAC programming.

Both those youngsters already out of school, and those leaving in the coming years, will feel the effects of retrenchment. Anticipated effects on mentally retarded youngsters and their families include lowered vocational aspiration and achievement of young people and significantly greater stress for families caring for these youngsters, both financial and emotional. There is also concern that, in the absence of family supports and vocational opportunities, increasing numbers of mentally retarded individuals may be institutionalized.

The discussion will now turn to the conclusions of our study and issue areas and services needs related to these.

CONCLUSIONS, ISSUES AND SERVICE NEEDS

This section of the report draws together the conclusions of the study process, presenting them with issues and relevant service needs where appropriate. As will be seen, a number of the major conclusions drawn from last year's study (Gordon, 1988) continue to hold true this year.

The decision was made to consider service needs related to conclusions, even if these proposals turn out to be largely moot, given the current retrenchment in services. Given the current climate, it highly unlikely that existing services will be expanded and new ones developed. It is more likely that existing services will be cut, leaving future cohorts of youngsters to fare far worse than those followed in this study, and the fates of those we have been following to more likely deteriorate than improve. Perhaps perversely, we are concentrating on service needs to some extent, because it is so clear that these exist. Is the case being overstated by saying that the outcome of neglecting such needs may prove to be severe - family break-down and new waves of institutionalization and homelessness?

Conclusion I: **The situation of our sample can be described as one of great stability and small changes. Also, although particular individuals moved toward achieving real work goals, the group as a whole did not make significant progress in this sphere over the year.** Individuals, especially those classified SPMR and TMR, tended to largely remain within the same living arrangements and work situations that they have been in since leaving school. Many of the living arrangements date from before school was completed - with parents or, in the case of many SPMRs, in residential institutions.

Lack of change has both good and bad elements. Unchanged situations can create secure, unthreatening environments but also, when they involve continued placement in minimally-challenging vocational options, can reflect stagnation more than stability. Situations need to be chosen with care and periodically reexamined to determine whether a balance between security and challenge is being maintained.

Issue: **Plans made for youngster's first year after school is completed are critical.** Especially for more disabled individuals, few changes in residential and vocational situations are made after initial placements are made.

Service needs: **Transition planning** for youngsters to help bridge the gap between school and work, and connect them with

high school careers. Post-school training and job placement options should be carefully chosen so as to utilize youngsters' full potential, as they are likely to be long-term, if not permanent. Placements should be periodically reviewed to determine whether they continue to be the best choices for meeting individual and family needs. If not, new vocational and residential options should be explored.

Conclusion II: The majority of mentally retarded school completers are firmly ensconced in their parents'/guardians' homes. As we found last year, a large percent of youngsters live with their parents and guardians after completing school, and parents are quite satisfied with this arrangement. That this remains the case two and three years after leaving school is confirmed by this year's findings. What also has been seen through this year's longitudinal view is that the degree of change in living arrangement since leaving school has been slight, although some few youngsters have moved from parents' home into more independent arrangements.

The study sample, thus, is firmly settled in parents' homes. Most parents see this situation as remaining the status quo for at least the next five years and have never looked into other alternatives. Half of the sample, however, realizes that the circumstances of their own death or infirmity would prompt a change in living arrangement and see living with sibling or in a CLA as the most likely residential choices. 29% see their own infirmity or death as a major concern in terms of their youngster's life and future.

Many of the families enthusiastically embrace the arrangement in which their youngster lives with them. Some of these arrangements, however, were clearly established by default - parents could not find a place in a CLA, could not find one which met their standards, felt that youngsters could not manage without them, felt that they could not afford other arrangements, or considered a CLA inappropriate but couldn't see their youngster living independently. The retrenchment of services currently taking place makes it highly unlikely that, even in those situations where the parents desire it, considerable numbers of these young adults will move to CLAs. Even placement from the emergency list currently takes years and we have seen aged parents in very precarious health continuing to provide care.

For some youngsters, we found living at home to preclude interaction with peers. We found a considerable subgroup of our youngsters living with their parents to have very meager social lives: 26% never interact socially with friends, and 11% do so only once a month or less. This is especially true of TMR youngsters, with almost half of those at home in these

interaction categories. This paucity of social interactions is, however, not true for everyone. 49% of youngsters living at home are reported to be interacting with friends at least once a week. It should be noted that the second most frequent service desired by parents in our study was for social and recreational programs for their youngsters.

These findings confirm, in part, those of other studies of mentally retarded adults living with their parents. One study reported that the offspring's "social lives were found to be extremely limited. Their companions were exclusively family members or other people with a mental handicap . . . . (Cattermole, et al, 1988). Another study found that "both the person and the parents led restricted lives, the person remaining highly dependent upon the parents and having little or no life outside the home". (Wertheimer, 1981, cited in Cattermole, et al, 1988).

Issue: Living at home appears a moot point - whether an enthusiastic choice, or one made by default in the light of a lack of available acceptable alternatives, **the majority of youngsters will remain at home with their parents and guardians for the foreseeable future.** The question becomes one of whether these families will be left to cope on their own or will be provided with significant support.

Service need 1: **Increased services to support youngsters and their families, while these families are caring for them.** These are largely subsumed under the rubric of "family support services", an area of increasing attention around the country. A recent editorial in the journal Exceptional Parent was titled, "Family Support: A Right for All Parents" (May/June 1989). The feeling is that the family caring for a disabled child is entitled to " 'anything it takes' to maintain the integrity of the family" (Knoll and Bedford, 1989). Families with handicapped youngsters differ from each other as much as any others, and have different needs, and would be benefit from different combinations of services.

Services especially desired by our respondents were social and recreational activities for youngsters and respite services for those more severely disabled. Parents also wanted their youngsters to receive more education in self-help areas: cooking, banking, mobility. For some, counseling, either of youngster or of parent, is desired. In addition, respite care was desired by parents of SPMR and TMR youngsters; housing opportunities by those with SPMR and PH/SED youngsters.

It should be stressed that it is precisely these non-residential services that are being singled out for the greatest retrenchment, while residential services are favored. As one father caring for a severely retarded young man in our sample

described to me in a long telephone discussion, if residential services are favored over in-home services, the break-down of families is promoted. More of these youngsters will be placed in institutions, when families break under the strains of care. The fact that residential placement is a vastly more expensive alternative to providing care at home might also be mentioned in this regard.

Service need 2: **Increased availability of places in acceptable CLAs.** For those parents who prefer it, and those who cannot provide care without enormous cost to themselves, physically or emotionally, the option for placement in CLAs needs to be expanded. Greater numbers of CLA slots need to be made available in facilities that meet families' criteria for supervision, proximity, social programming, staffing, independence, privacy, etc. The optimal solution would be one in which families' preferences for youngsters' living arrangement would be supported by appropriate services whichever option they choose. If it were for CLA, places would be made available in facilities that all concerned were comfortable with. If the choice were family care, family's could count on home-based services to share some of the burden and enrich the lives of youngsters and their families.

Service need 3: **Development of viable residential alternatives for youngsters for when parents are unable to provide care.** It is clear that the future housing needs of mentally retarded need to be addressed. Where will these individuals go when guardians can no longer care for them? Parents have indicated siblings as a favorite choice in that eventuality. The implications of this choice need to be assessed. Are siblings really going to take on this task; will the burden be passed down to another generation? If so, what will be the costs to siblings, what supports will they need and will such services be in place? The second choice indicated was CLAs. Will there be sufficient CLAs and what will their quality be? At present, there is a dearth of places in available CLAs, and a scarcity of alternatives that parents find acceptable.

Parents are looking for new solutions. One father who care for a severely handicapped son at home told us of his plans to establish a group home with some family money, whose board would consist of the son's siblings. This home would be open to individuals who have been living at home - one of the father's pet peeves is that established homes preferentially admit institution-based individuals. Similarly, a newspaper article (Blazina, 6/26/89) describes a group of parents in Ohio who have developed group apartments for their mentally retarded offspring, funded through a combination of state funds, regular family contributions for living expenses, and the youngsters' SSI benefits. Parents in both these situations assert the importance of parents retaining control of their youngsters' housing

situation. These types of alternatives need to be explored further and a menu of viable options, from which youngsters and their families could choose, developed. Innovative, creative approaches to developing and funding community-based group homes for the mentally retarded should be encouraged. If this occurs, sibling placement might be avoided, which would likely be beneficial for both the mentally retarded individual and the brother or, more likely, sister who would then not have to assume day-to-day supervision and care.

If such developments don't occur - and given the type of funding cuts we are now seeing and the priorities that are being supported, this may very well be the case - what will happen to these individuals as their parents age? Will institutionalization become the norm or, as has been predicated, should we "expect a second wave of homelessness" (, 1989)? A commitment is needed now to finding viable solutions to prevent such eventualities.

Conclusion III: **Competitive employment has proven a viable option for a considerable portion of the sample, especially the EMRs.** This year found 55% of EMRs employed; 60% of those who had been mainstreamed and 52% of those from centers. Just over half the workers work full time and all but one make minimum wage. Average earnings of $138/week are exactly 120% of 1989 poverty figures for individuals living alone, and so, as sole source of income would not permit these individuals to live independently. There are, however, individuals whose incomes are considerably above that level, notably among the mainstream cohort who, although earning average hourly wages only slightly higher than center-based individuals, work longer hours. (73% of mainstream workers work full time compared to 41% of center-based.) (The issue of disincentives for full-time work for individuals receiving SSI, although clearly relevant to this discussion, will not be covered here as it was explored in last year's report, Gordon, 1988).) Also, 60% of youngsters who had been in the same jobs for the last two years, received increases in hourly wage and/or weekly hours.

The paucity of movement toward competitive work found in the study makes the gains of those who have had post-school training all the more impressive, especially for center-based youngsters. With 14 out of the 17 youngsters who have had training working, ten of these with jobs in their field, the importance of post-school training becomes clear. Through post-school training, the jobs obtained are also more likely to be in fields, like nurse aid, that have potential for the future.

Center-based completers, being more dependent on formal contacts and programs to find jobs, appear to especially profit from formal placement and training initiatives. It is of note that 8 (28%) of the employed center completers are still working

in jobs they began within school-based cooperative education efforts and 21% received their jobs through post-school training programs.

Post-school vocational rehabilitation and placement is an area of great importance to parents, being both their number one concern in terms of their youngster's lives and the major areas in which they would like help from the social services. The cut-backs projected for the next few years are especially unfortunate as it is not likely that these youngsters, especially those from the centers, will be able on their own to find jobs with a future.

Issue: **Competitive employment appears to offer the greatest potential for mentally retarded youngsters, in terms of use of their abilities, financial independence and entrance into the mainstream of society. Initiatives should be encouraged which provide opportunities for obtaining and keeping jobs for the greatest possible number of mentally retarded school completers.**

Service needs: **Continued in-school cooperative education, expansion of post-school vocational programming, study to determine jobs suitable for the mentally retarded which have potential for long-term job retention, increase in the number of youngsters receiving training in fields with a future.**

Conclusion IV: **The work-related situations of most of the sample are not congruent with the latest thinking in terms of the vocational potential of the mentally retarded.** "Recently described professional expectations . . . hold that most persons who are mentally retarded can effect transition into the mainstream of employment". (Hill et al, 1987) Supported employment has been embraced around the country as the way in which the mentally retarded can be placed and retained in jobs. The assertion is that individuals with all degrees of handicap can be successfully placed in jobs, given that they are provided necessary supports of all kinds.

Although there are supported work programs in Allegheny County, there is little evidence in the present study that such initiatives have affected local school completers. (See Gordon, et al, 1987 for a full description of supported work in Allegheny County.) Some findings from our study that are not congruent with state-of-the-art vocational initiatives for the mentally retarded:

* 48% of TMRs are in WACs and the vast majority have been in these centers since leaving school.

* EMRs were placed in sheltered workshops within the past year.

* 28% of the non-SPMR sample is idle, largely because these individuals are seen as not having the ability to handle work situations.

* Only 2 individuals in our sample are in supported employment. Neither moved into their jobs in the current year. A third individual lost her job when a sympathetic store manager was replaced by an unsympathetic one who made things hard for her.

New initiatives thus, appear largely to have passed the sample by. The new developments stress moving those currently in WACs and sheltered workshops out of such placements, and not continuing to place people, certainly not individuals at the level of EMRs, in these situations. The TMRs especially appear to locked in low-level programming. The reasons that have been given for the idle component of our sample's not working are precisely those that supported work advocates do not accept as legitimate, feeling that such individuals can work given appropriate assistance.

It is likely that parent attitude is a factor in youngsters being placed in and remaining in WAC and sheltered workshop situations. Hill (1987), a professional on the forefront of support employment has said:

> It is probable that the attitudes of these parents have been influenced by the highly restrictive/protective services traditionally supplied to the person who are moderately retarded, particularly at the school-age level and also often at the adult service level in the form of the activity center or development center placement. . . .
>
> General results show that, at present, parents' expectations do not concur with the recently described professional expectations which hold that most persons who are mentally retarded can effect transition into the mainstream of employment.
>
> (See Gordon, 1988 for further discussion.)

Parent preference for available placements is liable to be especially true when long waiting lists are the norm. Parents with youngsters at home wait anxiously, usually for years, for a place to become available in a program that reliably provides activity on a daily basis. They are understandably eager to grab it with both hands and are not likely to hold out for something with more ambitious vocational goals for their youngster. Although perhaps ultimately wishing for a more ambitious future for their youngsters, parents may gratefully settle for a

placement that promises permanence, stability, safety and proximity to home. Once in the program, parents may tend to hold on to the sure thing and understandably not risk their youngster in new programming that, if it doesn't work out, may leave them again on the bottom of a waiting list.

Where supported employment options made more available, it would be hoped that competitive employment would become a possibility for many more individuals, from different exceptionality groups, who can not achieve the transition to jobs on their own.

Service needs: Working with parents to explore additional vocational options for their youngsters (described more fully in Gordon, 1988), making many more places available in supported work programs, moving people presently in WACs and workshops to more ambitious vocational options, and placing individuals directly from school into supported employment.

This discussion has clearly been very ambitious in suggesting service needs in many areas. The attempt has been to present ideal circumstances, to encourage thinking and discussion unhindered by fiscal and philosophical realities. In any case, this discussion may largely be moot in the light of retrenchment of services. If facilities are not going to be expanded, and are even going to be cut, what we are now experiencing may be the best that we can hope for, and choice may be even more restricted in the future.

STUDY SECTION I

SUMMARY OF FINDINGS

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This year's work expands the follow-up begun of mentally retarded school completers begun in 1987 and continued in 1988. Parents and guardians of youngsters who completed their educations in the Allegheny Intermediate Unit's special educations programs in 1985-1986 and 1986-1987 were contacted. This is the third year of follow-up for the 1985-1986 group and the second year of follow-up for the 1986-1987 group. As in previous years, information was gathered on youngster's present living and work situations, and job and training involvement over the year. New areas were also explored this year. These included parents' satisfaction with present living arrangement, plans for the future, residential placement out of the home, youngster's social life as well as parent's concerns for the future and desired help from social services. Research findings are summarized below.

LIVING ARRANGEMENT

SPMR: 62% live in institutions, 28% live with their parents and 10% in group living arrangements or CLA's.

Total non-SPMR sample: 73% of the total non-SPMR sample lives with parents or guardians, 9% lives independently, 9% is living in group situations or CLAs, and 5% is institutionalized.

EMRs: 75% of all EMRs presently live with parents or guardians. 15% live independently. The remainder live in CLAs (3%), with other relatives (3%), or alone (1%). Of the mainstream EMRs, 72% are living with parents or guardians, 24% independently, and one individual (4%) with a relative.

TMRS: The TMRs live in one of three situations: with their parents or guardians (77%), in institutions (13%), and in group arrangements or CLAs (10%). None live independently.

Changes in living arrangement

The living arrangements of the school completers have been stable over the years of the study. The vast majority of youngsters has been living the same arrangement since leaving school.

SPMR: No youngster has had a change in living arrangement in the course of the study.

EMRs: Overall, the living situations of the EMRs in the study are characterized by constancy, with 81% remaining in the same arrangement since leaving school. A slight tendency toward increased independence of living arrangement is seen, espécially for those out of school the longest, the '86 cohort.

TMRs: The TMRs exhibit an even greater constancy in living arrangement than the EMRs. Overall, 92% of the sample has been living in the same situation since leaving school.

YOUNGSTERS LIVING WITH PARENTS OR GUARDIANS

A consistent finding of our follow-up research has been the extremely high percentage of youngsters living with their parents or guardians after leaving school, percents considerably higher than those found in comparable studies. A number of variables were added to this year's study to further explore this situation.

Parents' satisfaction with living arrangement: Parents clearly tend to be satisfied with having their children live with them. 84% of parents of EMR youngsters and 70% of those of TMR youngsters, declared themselves very satisfied; 11% of EMR parents and 22% of TMR as somewhat satisfied. Only 6% of parents of EMR youngsters and 8% of parents of TMR individuals were dissatisfied to some degree.

Frequency of youngster's social interaction: 26% of the total sample of youngsters living with their parents never interacts socially with friends, 11% only once a month or less. 49% socializes with friends at least once a week. TMRs living with their parents or guardians have the largest percent of individuals having minimal social interactions. 30% never interact with friends, and 16% only once a month or less, adding to 46% having very meager social interactions. 49% of this group interacts socially with friends on at least a weekly basis.

Where the youngster will be living in 5 years: Parents were asked where they thought their youngsters would be living in five years. Many anticipate that their youngsters will remain with them: 76% of parents of TMR youngsters, 61% of parents of EMR center completers and 44% of EMR mainstream completers. Parents of TMR youngsters who anticipate a change in living arrangement regard CLAs or group arrangements as the most likely situation for their youngsters (16%). Parents of EMR youngsters who expect a change in living arrangement regard an independent living situation as most likely for their youngsters: 16% of parents of center-based completers and 39% of mainstream completers.

Whether parents have explored the possibility of youngster's living away from home: All parents and guardians whose mentally retarded youngster lived at home with them were asked whether they had ever explored the possibility of her/her living away from home. For the total sample, including all exceptionality groups, 37% of the parents whose youngster lived at home with them had explored this possibility, 63% had not. 46% of parents of TMR youngsters at home, 32% of parents of center-based EMR youngsters, and 17% of parents of mainstream EMR youngsters had explored this possibility.

Steps taken: Those parents/guardians who indicted that they had explored the possibility of their youngsters' living away from home were asked what steps they had taken. Half had contacted counselors, 30% had been placed on waiting lists for facilities, and 25% had discussed the possible move with their youngster. 15% had discussed the potential move with family member, 15% had applied for placement and 13% had visited a facility.

Reasons why not living away from home: Parents who indicated they had explored the possibility of their youngster living away from home were asked why he/she was not living away from home. Almost half the parents said that they decided against it for reasons that included: satisfied with situation as it is, facility is an unsafe area, and potential loss of Social Security benefits if youngster left home. Other grounds cited were: on waiting list (22%), youngster did not want to (21%), no openings (10%), youngster had previously been away and had returned home (7%), and absence of suitable facilities (5%).

Critical qualities of a CLA: Parents were asked the qualities that a CLA or group apartment would have to have for them to consider it for their youngster. The most frequent response (50% of respondents) was good supervision. Next was that the facility be close to home (12%).

Circumstances under which parents would consider youngster living away from home: All parents and guardians whose youngsters live with them were asked the circumstances under which they would consider their living away from home. The four most frequent responses were: in event of parent's death (49%), should parents become infirm (25%), if youngster wants to (13%), and under no circumstances (9%).

Where youngster would live if these circumstances occurred: A related question asked all parents of youngsters living at home was the youngster's likely living arrangement were these circumstances to occur. The findings for those 50% of parents who cited their own death or infirmity were: sibling (42%), CLA (36%), other relative (6%), residential institution (6%), independently (4%) and don't know (11%).

WORK SITUATION

Present work situation

SPMR: 83% are in activity centers, the remainder have no activity. Youngsters in no activity are primarily those living at home.

Total non-SPMR sample: The major activity categories for the total non-SPMR sample are competitive employment (32%), no activity (28%), activity center (20%) and sheltered workshop (15%). The competitive employment category is almost exclusively the province of EMR individuals, TMRs dominate the activity center category, and individuals categorized SED/LAP or PH are the most likely to be idle.

EMRs: 55% are employed, either in competitive or in supportive employment, 27% are idle, 9% are in sheltered workshops, and 4% in activities centers. The work-related activity situation of the mainstream cohort falls almost exclusively into two categories, competitive employment (60%) and no activity (36%).

TMRs: The most common work activity situation of TMRs is activities center, with 48% in such centers. 27% are in no work-related activity, 19% are in sheltered workshops, 4% are in competitive employment and 2% is in training.

STABILITY AND CHANGE

If we look at our three major exceptionality groups in terms of stability and change in the two major life areas of living situation and work, we find:

SPMR: All individuals have been in the same living and activity situations since leaving school. No change in either living arrangement or activity situation has been seen for any SPMR individual in the course of the study.

TMR: The TMR individuals also show great stability in the major areas of life; living arrangement and work-related situation. 85% of the total TMR sample (41/48 individuals) have been in the same living and work situations since leaving school. Only 7 TMR individuals (15%) have had any change in living or work arrangement in the course of the study.

EMR: The EMR exceptionality is the only one showing some degree of change in living and work arrangement. The majority of

EMR individuals (57%) have been in the same living arrangement and work-related situation since leaving school. 43% of the EMR sample has experienced a change in these conditions during the course of the study.

COMPETITIVE EMPLOYMENT

Present employment:

44 of the 163 youngsters (27%) in the sample are employed in competitive or supported work. 91% of those competitively employed are EMRs.

Types of Jobs: Restaurants, including fast food outlets, are an important source of employment. 32% of jobs are in restaurants. 23% of workers are in health care institutions, such as nursing home or hospitals. This appears to be a growing sector of employment for MR youngsters. 6 of the 10 employed in these institutions obtained their jobs this year.

Hours: Over half (55%) of those with a job are working full-time (at least 35 hours per week). 14% are working less than 20 hours a week. Average hours for the workers is 32.6 hours a week.

Hourly wage: The average hourly wage of the workers is $4.13/hr. 8 workers (18%) earn at or below minimum wage, $3.35/hr. 7 individuals (16%) earn $5.00/hr or more.

Job referral: The workers obtained their jobs through family or friend contacts (25%), youngster's inquiry (20%), training programs (18%), in-school coop job placements (18%) and through training program placements (18%).

Transportation to work: 72% of the workers get to their jobs independently by using public transit, walking, or driving themselves. 20% ride with a friend or relative

Improvement in wages or hours: 25 of the workers are working in the same job they held last year. 15 of these (60%) have received increases in their hourly wages and/or weekly hours.

TRAINING AND PLACEMENT

Post-school training: Seventeen youngsters have completed vocational training programs since leaving school. 12 of these (71%) are center completers, 5 (29%) were mainstreamed.

Type of training: The most popular training programs for our study subjects were Nurse's Aide (35%), Janitor/Custodian (24%) and Food Service (18%). Other fields studied were, commercial art, machinist, cooking and business.

Jobs in field of training: 14 of the 17 trainees (82%) obtained a job after completion of their training; 10 of the these in the fields in which they were trained.

Center Completers - The Importance of Training: Training has been an important steppingstone to employment for many center completers. Center EMRs and SED/LAPs who received post-school vocational training were more likely to be employed than those who did not (p=.013).

IDLE YOUNGSTERS

non-SPMR: 38 individuals, 28% of the sample, are in no work-related placement. 31 of these (82%) have been idle each time they have been contacted by the study.

Reason for leaving last job: The major reason for leaving previous job was "could not handle work" (31%). Other reasons include dissatisfied with an aspect of work conditions (15%), dismissed (15%), and program/job ended or terminated (15%).

Reason why not working at present: As viewed by the parent or guardian, the reason that a youngster is not working now is most often that he/she cannot handle the work situation, that his/her disability prevents employment, or that his/her skills or ability are not sufficient for work (39%). Youngster's attitude (16%), work not being available or being on waiting lists (13%), and have not pursued work (13%) were also cited by respondents.

How the idle spend their time: The two most common activities mentioned by respondents are doing chores and running errands (50%) and watching television (28%). The next most frequent activities (19% each) are reading, drawing and listening to music; shopping; and walking or exercise. 16% of these youngsters are described as "hanging around". 6% each spends some of their time job-hunting, sleeping, in volunteer work, caring for their baby, or sitting around.

PARENT CONCERNS AND DESIRED HELP FROM HUMAN SERVICES

Areas of greatest concern: Work and vocational training is the most frequently voiced area of concern (30%). Parents of

both EMR groups, mainstream (32%) and center (38%), and the TMR group (29%), were most apt to see this as an area of concern. Next most frequently cited by respondents was a concern for their own infirmity or death (29%). Higher percentages of parents of more severely handicapped youngsters mentioned this - TMR (43%), PH/SED/LAP (33%) and notably SPMR (56%). Physical health of their youngster was cited by 17% of respondents (44% of PH/SED and 29% of TMR). Additional areas of concern include: housing and living arrangement (14%), social life and social skills (12%), finances and financial self-sufficiency (12%), and generally coping with life and taking care of oneself (12%).

Desired help from human services: Only a few types of social service programs were desired by considerable numbers of parents. Additional work and training opportunities for their handicapped youngsters was most frequently mentioned (38%). The desire for such assistance was especially noted by mainstream (48%) and center EMR (40%) parents, and also by those with PH/SED children (56%). The next most frequently requested area of social service programming was social and recreational programs for youngsters (17%). Third most frequently cited by parents was additional education in basic life areas (12%). Additional help from social services desired by particular parent groups include respite care (SPMR, 22% and TMR, 14%) and housing opportunities and residential facilities, (SPMR, 22%, PH/SED, 21%). 22% of the sample wants no help from the human services system.

STUDY SECTION II

THREE YEARS OF FOLLOW-UP OF MENTALLY RETARDED SCHOOL COMPLETERS

THREE YEARS OF FOLLOW-UP OF MENTALLY RETARDED SCHOOL COMPLETERS

This year we expanded the follow-up begun in 1987, and continued in 1988, of mentally retarded (MR) school completers of the Allegheny Intermediate Unit's (AIU) special education programs. (Gordon, Goldbach and Katz, 1987; Gordon, 1988). Two cohorts of youngsters were followed; those who completed school in the 1985-1986 and in the 1986-1987 school years. The former group, thus, was studied for the third year; the latter for the second. Youngsters with an MR involvement of any degree who had completed their educations at one of the AIU's special education centers in these school years were followed. Also included in the cohort of 1986-1987 completers were youngsters with an MR disability who had been in mainstreamed classes under AIU auspices in regular area high schools. These individuals were all classified educable mentally retarded (EMR). In that they were mainstreamed, these youngster were considered, in the main, less handicapped and better able to be integrated than their peers in the special education centers.

The Study Subjects

Center completers: Center completers finished their educations at the six special education centers of Allegheny Intermediate Unit during the 1985-1986 and 1986 - 1987 school years. These centers, located around the county, serve the handicapped children of the school districts of suburban Allegheny County which are under the auspices of the Allegheny Intermediate Unit. Less disabled youngsters, and those judged able to handle integration with nondisabled peers, are mainstreamed into district schools. The centers, then, serve the more severely disabled, those with multiple handicaps, those with emotional problems as well as developmental delays, and those otherwise unable to be integrated into a mainstreamed setting. The study population was comprised of all students who left school in the identified year who had any degree of mental retardation (MR), whether as a primary or secondary disability. While in school, the youngsters were classified into exceptionality groups using state standards. Although also based on functional ability and thus, having a 5% leeway, the major groups are determined by I.Q.: Severely Profoundly Mentally Retarded (SPMR) - I.Q.25 and below; Trainable Mentally Retarded - I.Q. range roughly 25+ to 50; Educable Mentally Retarded (EMR) - I.Q. range roughly 50+ to 80. Additional groups are Physically Handicapped (PH), and Social or Emotional Disabled/Learning and Adjustment Problem (SED/LAP). Our study sample only included PH and SED/LAP individuals who were also mentally retarded to some degree. Students who graduated, received a certificate or left school without official termination were all included in the follow-up.

Mainstreamed students: Mainstreamed students completed their educations in an EMR class under the auspices of the AIU, in one of 12 district high schools. These classes are physically located within a regular high school. These students typically have their own programming within the high school building, but may interact with non-handicapped peers in some non-academic classes, at lunch, extra-curricular activities, and in the normal flow in hallways. Students who graduated, or who left school without official termination at any time during the school year, were included.

Data Collection: Interviewing Parents and Guardians

The phone numbers taken from school records and roster lists and used in the 1988 follow-up, were again checked for accuracy against listing in telephone directories and the Cole's Directory. Major attempts were made to contact parents, and guardians. If necessary, numerous callbacks, at different times of the day, and different days of the week, were made to the identified numbers. In addition, interviews were scheduled at the interviewee's convenience. If the youngster was in a residential institution, a supervisor at the institution was interviewed rather than the parents. In the case of youngsters in group living situations or Community Living Arrangements (CLAs), sometimes an individual in charge was interviewed, sometimes a parent, and sometimes both were interviewed.

The same questionnaire was used to interview all respondents. It was a modified version of that used in previous years. Basic information was kept on youngster's present living and work situations, and job and training program involvement over the year. In addition, a considerable number of questions were added which explored new areas. A number of these arose out of our consistent finding that a large percent of our sample lived at home with parents or guardians. We wanted to investigate this further and developed questions which determined respondents' satisfaction with this situation, plans for the future, exploration of housing alternatives, etc.

The Study Sample

* The overall return rate of the study of 1987 completers was very high. The researchers were able to reach 90% of the center completers and 83% of those who had attended mainstreamed classes (see tables pages and).

* In total, 163 out of last year's sample of 183 cases were contacted and successfully interviewed, for an overall

response rate of 89%. Most (85%) of the attrition was due to disconnected or wrong numbers, indicating that the families involved experienced a change of location or circumstances (see table p.).

* The loss of 15 cases from the two center cohorts had virtually no effect on the racial configuration of the sample, which was 86% white last year and 87% white this year (data on race was not provided for mainstream students).

* Eight (53%) of the lost cases were from two centers, Mon Valley and Eastern Area, whose catchment areas contain low-income neighborhoods. Families of EMRs in these areas have proven to be difficult to locate in each year of the study. There are, altogether, 15 fewer EMRs in this year's sample: 10 from the two center cohorts, 4 from the mainstream cohort, and 1 mainstream case which was misclassified as MR last year. The study sample, then, tends to be somewhat less representative of youngsters whose families are in the lower, rather than the higher wealth rating categories.

* The mainstream cohort experienced a loss of five cases, all female, changing the male representation from 57% to 68%.

* The characteristics of all respondents are shown in the table on page .

COMPARISON OF RESPONDENTS AND NON-RESPONDENTS

Center Completers, 1986 and 1987 Cohorts

	RESPONDED	DID NOT RESPOND	TOTAL	PERCENT RESPONDING
SCHOOL				
Mon Valley	23	3	26	(88)
Eastern Area	10	2	12	(83)
Sunrise	19	3	22	(86)
Middle Road	41	1	42	(98)
Western Hills	25	3	28	(89)
Pathfinder	20	3	23	(87)
WEALTH RATING				
Very High	23	2	25	(92)
High	33	1	34	(97)
Middle	17	4	21	(81)
Low	31	2	33	(94)
Very Low	14	4	18	(78)
Unknown	20	2	22	(91)
PRIMARY EXCEPTIONALITY				
EMR	50	10	60	(83)
TMR	48	4	52	(92)
SPMR	29	0	29	(100)
PH	4	0	4	(100)
SED/LAP	7	1	8	(88)
SEX				
Male	92	7	99	(93)
Female	46	8	54	(85)
RACE				
White	120	11	131	(92)
Black	16	4	20	(80)
Asian	2	0	2	(100)
Total	138	15	153	(90)

COMPARISON OF RESPONDENTS AND NON-RESPONDENTS
Mainstream Completers, 1987

	RESPONDED	DID NOT RESPOND	TOTAL	PERCENT RESPONDING
WEALTH RATING				
Very High	3	0	3	(100)
High	7	1	8	(88)
Middle	2	1	3	(67)
Low	4	2	6	(67)
Very Low	6	0	6	(100)
Unknown	3	1	4	(75)
SEX				
Male	16	0	16	(100)
Female	9	5	14	(64)
Total	25	5	30	(83)

NON-RESPONSE SUMMARY 1989 SAMPLE

	1986 Center		1987 Center		1987 Mainstream		Total	
	#	(%)	#	(%)	#	(%)	#	(%)
Completed Interview	75	(93)	63	(88)	25	(83)	163	(89)
Phone Problem*	6	(7)	7	(10)	4	(13)	17	(9)
Refused			2	(3)			2	(1)
Incorrectly Classified as MR Originally					1	(3)	1	(1)
	81	(100)	72	(100)	30	(100)	183	(100)

* Disconnected, wrong number, etc.

THE 1989 STUDY SAMPLE
Center Completers

	1986 Center (N=75)		1987 Center (N=63)		Total (N=138)	
	#	(%)	#	(%)	#	(%)
School						
Mon Valley	18	(24)	5	(8)	23	(17)
Eastern Area	4	(5)	6	(10)	10	(7)
Sunrise	7	(9)	12	(19)	19	(14)
Middle Road	24	(32)	17	(27)	41	(30)
Western Hills	14	(19)	11	(17)	25	(18)
Pathfinder	8	(11)	12	(19)	20	(14)
Primary Exceptionality						
EMR	23	(31)	27	(43)	50	(36)
TMR	25	(33)	23	(37)	48	(35)
SPMR	19	(25)	10	(16)	29	(21)
SED/LAP	6	(8)	1	(2)	7	(5)
PH	2	(3)	2	(3)	4	(3)
Race						
White	63	(84)	57	(90)	120	(87)
Black	10	(13)	6	(10)	16	(12)
Asian	2	(3)			2	(1)

THE 1989 STUDY SAMPLE
Center and Mainstream Completers

	1986 Center (N=75)		1987 Center (N=63)		1987 Mainstream (N=25)		Total (N=163)	
	#	(%)	#	(%)	#	(%)	#	(%)
Sex								
Male	54	(72)	38	(60)	17	(68)	109	(67)
Female	21	(28)	25	(40)	8	(32)	54	(33)
Birth Year								
1963	1	(1)					1	(1)
1964	26	(35)					26	(16)
1965	38	(51)	17	(27)			55	(34)
1966	4	(5)	35	(56)			39	(24)
1967	3	(4)	4	(6)	4	(16)	11	(7)
1968	1	(1)	2	(3)	15	(60)	18	(11)
1969			2	(3)	6	(24)	8	(5)
1971	1	(1)					1	(1)
Unknown	1	(1)					1	(1)

FINDINGS

LIVING ARRANGEMENT

Present Living Arrangement

SPMR: The living arrangements of the 29 SPMR youngsters in the sample are as shown in the table below. The majority (62%) live in institutions, 28% live with their parents and 10% in group living arrangements or CLAs. No change in living arrangement has been seen for SPMR youngsters in the course of the three years of the study; all SPMR youngsters in the sample have remained in the same living arrangement since completing school.

SPMR LIVING ARRANGEMENTS

	1986 Cohort		1987 Cohort		Total	
Living Arrangement	#	(%)	#	(%)	#	(%)
Parent/Guardian	3	(16)	5	(50)	8	(28)
CLA, Group Home	3	(16)			3	(10)
Institution	13	(68)	5	(50)	18	(62)
Total	19	(100)	10	(100)	29	(100)

Total non-SPMR sample: The table below presents the living arrangements for all other groups in the sample. Almost three-quarters of the total non-SPMR sample lives with parents or guardians and 9% lives independently - alone, with spouses or roommates or, in the case of one individual, is in the Navy. An additional 9% is living in group situations or CLAs, and 5% is institutionalized. Looking at living arrangements characteristic of the different exceptionalities, we see that, unlike other groups, physically handicapped tend to live in group arrangements or CLAs, and TMRs to live with their parents or in group or institutional settings. Only for EMRs do we see a significant minority (15%) living independently; alone, with spouses and roommates, and in the Navy.

NON-SPMR LIVING ARRANGEMENTS

Living Arrangement	EMR	(%)	TMR	(%)	PH/SED	(%)	Main-stream	(%)	Total	(%)
Parent/Guardian	38	(76)	37	(77)	5	(45)	18	(72)	98	(73)
Independent	4	(8)			1	(9)	6	(24)	11	(8)
CLA, Group Home	2	(4)	5	(10)	5	(45)			12	(9)
Institution	1	(2)	6	(13)					7	(5)
Other	2	(4)					1	(4)	3	(2)
Not known	3	(6)							3	(2)
Total	50	(100)	48	(100)	11	(100)	25	(100)	134	(100)

The discussion of living arrangements will now focus on EMRs and TMRs. As in past years of the study, the samples of PH and SED/LAP are noted to be too small to permit individual discussion of specific variables.

EMRs: A full 75% of EMRs presently live with parents or guardians. As was noted above, 15% live independently. In addition, 3% are in CLAs, 1% in institutions, and 3% live with other relatives. The living arrangements of 4% are unknown. Looking the cohorts individually, we see that 70% of the '86 center group lives with parents or guardians, 22% lives independently (alone, with spouse or in the Navy), and 1 (4%) is in a group situation or CLA. The '87 center group has an even higher percent living with family (82%), no one living independently, and one person each (4% each) in a group situation or CLA, and in an institution. In the mainstream group, which also completed school in 1977, 72% is living with parents or guardians and 24% independently - alone, with spouse and children or with a roommate. One individual (4%) is living with a relative.

LIVING ARRANGEMENT OF CENTER AND MAINSTREAM EMRs

	1986 Center		1987 Center		Main-stream		Total	
Living Arrangement	#	(%)	#	(%)	#	(%)	#	(%)
Parent/Guardian	16	(70)	22	(81)	18	(72)	56	(75)
Independent	5	(22)			6	(24)	11	(15)
CLA, Group Home	1	(4)	1	(4)			2	(3)
Institution			1	(4)			1	(1)
Other relative			1	(4)	1	(4)	2	(3)
Not known	1	(4)	2	(7)			3	(4)
Total	23	(100)	27	(100)	25	(100)	75	(100)

TMRS: The TMRs live in one of three situations: with their parents or guardians (77%), in institutions (13%), and in group arrangements or CLAs (10%). None live independently. The two cohort groups are very similar in terms of this breakdown. For the 1986 group, the percentages in the three types of living arrangements are 76%, 12% and 12% respectively. For the 1987 group, they are 78%, 13% and 14% respectively. Figures for the TMR living arrangements on shown in the table on the following page.

TMR LIVING ARRANGEMENTS

Living Arrangement	1986 Cohort #	(%)	1987 Cohort #	(%)	Total #	(%)
Parent/Guardian	19	(76)	18	(78)	37	(77)
CLA, Group Home	3	(12)	2	(9)	5	(10)
Institution	3	(12)	3	(13)	6	(13)
Total	25	(100)	23	(100)	48	(100)

Changes in living arrangement

The living arrangements of the school completers proved to be quite stable over the years of the study. The vast majority of youngsters have been in the same arrangement since leaving school. As was noted above, no SPMR youngster has had a change in living arrangement over the course of the study. As will be seen below, the EMR and TMR groups have also proved quite stable in their living arrangements.

EMRs: 17 of the 23 youngsters in the '86 center cohort (74%) have been living in the same situation for the 3 years since they have left school - 16 of these with a parent or guardian, and one in the Navy. For five of the remaining youngsters, there has been some movement towards more independent living situations: 2 (9%) have been living with spouses for the past two years, 2 (9%) live alone, and 1 (4%) is in a CLA for the first time this year. The situation of one youngster remains unclear. For the '87 center cohort, 23 of the 27 (85%) have been in the same type of living situation since leaving school - 21 with parents and guardian, one with an aunt, and one moved from one institution to another. The changes in living arrangement noted this year are mixed: one youngster who had been living alone is now with parents or guardians and one individual moved from parents or guardians to a CLA. Perhaps surprisingly, the mainstream group has proven to have the most stable living arrangements of all. 22 of the 25 youngsters (88%) in this group have been in the same living arrangements for the two years since they have left school - 18 with parents or guardians, 3 with spouse/children and 1 alone. The 3 whose arrangement changed this year all moved out of their parents' or guardians' homes. One each now lives alone, with a roommate and with an aunt. Overall, then, the living situations of the EMRs in the study are characterized by constancy, with 81% remaining in the same arrangement since leaving school. A slight tendency toward increased independence of living arrangement is seen, especially

for those out of school the longest.

TMRs: The TMRs exhibit an even greater constancy in living arrangement than the EMRs. Overall, 92% of the sample (44 individuals) has been living in the same situation since leaving school - 37 in their parents' or guardians' home, 3 in group situations or CLAs, and 4 in institutions. 4 individuals have experienced a change in living situations since leaving school: one from the '86 cohort moved into a CLA last year and one did so this year. One from each of the cohorts, '86 and '87, entered institutions this year. In terms of each TMR cohort then, extreme stability is seen in respect to living arrangement since leaving school. There is, however, slightly greater change in living arrangement seen in the group out of school for three years: 88% of the '86 cohort, and 96% of the '87 cohort, has been in the same living situation since leaving school.

YOUNGSTERS LIVING WITH PARENTS OR GUARDIANS

A consistent finding of our follow-up research has been the extremely high percentage of youngsters living with their parents or guardians after leaving school. These percents have been considerably higher than those found in studies in other parts of the country on similar populations. (Gordon et al, 1987) A number of new variables were added to this year's study to explore this situation further. Parents views on and interest in alternative living arrangements for their youngsters were sought. Parents were asked their degree of satisfaction with their youngster's present living arrangement, the frequency of their youngster's social interaction with friends, and where they saw their youngster living in five years. They were also asked whether they had ever explored the possibility of the youngster's living away from home and if so, the steps they had taken and the reasons why their child was not living away from home at present. The circumstances under which respondents would consider their youngster's living away from home, where he/she would be likely to go if these circumstances occurred, and the qualities they felt were important in a CLA or group apartment were also queried.

The findings on these variables will be discussed primarily in regard to EMR and TMR youngsters. For some variables, however, youngsters of all exceptionality groups who live with parents or guardians are included.

Parents' satisfaction with living arrangement: The findings in respect to this variable are unequivocal. Parents and guardians describe themselves as satisfied with having their children at home with them. (See table below.) 84% of parents of EMR youngsters and 70% of those of TMR youngsters, declared themselves very satisfied. An additional 11% of EMR parents and 22% of TMR were somewhat satisfied with this arrangement. Only 3 (6%) parents of EMR youngsters and 3 (8%) of parents of TMR individuals were dissatisfied to some degree.

PARENT/GUARDIAN SATISFACTION WITH LIVING ARRANGEMENT
EMRs and TMRs Living at Home

	EMR		TMR		TOTAL	
	#	(%)	#	(%)	#	(%)
Very Satisfied	47	(84)	26	(70)	73	(78)
Somewhat Satisfied	6	(11)	8	(22)	14	(15)
Somewhat Dissatisfied	2	(4)	2	(5)	4	(4)
Very Dissatisfied	1	(2)	1	(3)	2	(2)
Total	56	(100)	37	(100)	93	(100)

When asked to explain this answer, 23% of parents gave replies which stressed that they did not consider their youngster a problem e.g. "he's no problem", "he's not much trouble", "he's not a burden". Next frequently (18%), respondents asserted that the youngster belonged at home: "he's my son", "this is where he belongs", "I wouldn't have it any other way". Almost as frequently (16%) parents gave answers which indicated they enjoyed having their youngster living with them: "I love it", "she is a blessing", "I enjoy him". 13% felt that home was the best place for their youngster. Other types of answers stressed that the youngster was most comfortable at home (11%), that both parent and child liked the arrangement (10%), and that he/she could not manage alone (9%). There were some comments that indicated difficulties with the situation as well. (Some parents stating that they were somewhat satisfied with the situation also indicated difficulties.) 6% felt being at home was not good for the youngster: "he's just vegetating", "she's not too happy", "I'd rather see him independent". 6% cited their own difficulties with the situation: "her behavior is bad, she's difficult to manage", "things are getting harder as we get older", "it limits me because I can't work". 6% seem to consider an alternative living situation to be preferable: "he would be better off on his own because he will have to be sooner or later", "group homes are full", "I'd like to see him in a group home; because of financial considerations, he must live at home". More parents of TMR (17%) and mainstream EMR youngsters (18%) made negative comments about having their youngster at home with them than did parents of youngsters in other groups.

(Some parents whose children were in CLAs also commented on that living arrangement. Positive comments included "its a nice home and a nice neighborhood, he likes it", "he lives with boys his same age", "he seems to be well taken care off", and "he's learned to be independent". Negative comments were, "I'd like him to be closer to home, I worry about safety", "his behavior requires supervision", and "he does not cooperate".)

Frequency of youngster's social interaction: Parents were asked how often their youngster interacts socially with friends outside of work activity hours. Family activities and gatherings were excluded from this accounting. The findings are presented below. It appears that there are two distinct patterns seen for sample subjects: one portion of the sample interacts very seldom or never with friends, the other interacts on a regular basis. Looking at the total column, it can be seen that over a quarter (26%) of the sample never interacts socially with friends. An additional 11% interacts only once a month or less. Almost half the sample (49%) living at home interacts with friends at least once a week. In regards to the different exceptionality groups, it may be seen that half the mainstream group socializes with

friends at least weekly. However, 17% interacts only once a month or less, and the same percent has no interaction with friends. Over a quarter of the center-based EMRs (26%) never interacts with friends, an additional 5% socializes only once a month or less. Almost half of this group (49%) interacts at least weekly. TMRs living with their parents or guardians have the largest percent of individuals having minimal social interactions. 30% never interact with friends, and 16% only once a month or less, adding to 46% with a very meager social life. However, almost half this group (49%) interacts socially with friends on at least a weekly basis.

FREQUENCY OF INTERACTION WITH NON-RELATIVES OUTSIDE OF WORK SETTING

Non-SPMR Youngsters Living at Home

	MAINSTREAM		EMR		TMR		PH		SED/LAP		TOTAL	
Frequency of Interaction	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)
Never	3	(17)	10	(26)	11	(30)			1	(25)	25	(26)
Once per month or less	3	(17)	2	(5)	6	(16)					11	(11)
2-4 times per month	2	(11)	4	(11)	2	(5)	1	(100)			9	(9)
1-2 times per week	3	(17)	10	(26)	9	(24)			1	(25)	23	(23)
3-6 times per week	3	(17)	7	(18)	7	(19)			2	(50)	19	(19)
Daily	3	(17)	2	(5)	2	(5)					7	(7)
Don't know	1	(6)	3	(8)							4	(4)
	18	(100)	38	(100)	37	(100)	1	(100)	4	(100)	98	(100)

Where the youngster will be living in 5 years: In order to get a sense of the degree to which parents saw their children's living with them as permanent or were making plans for a change, they were asked where they thought their youngsters would be living in five years. Parent responses are presented in the table below. It can be seen that many of the parents anticipate that their youngsters will remain with them: 76% of parents of TMR youngsters, 61% of parents of EMR center completers and 44% of EMR mainstream completers. The living arrangements of a minority of youngsters are seen as changing in the next five years. Parents of TMR youngsters living at home who anticipate a change in living arrangement regard CLAs or group arrangements as the most likely situation for their youngsters, with 16% anticipating such a move. Parents of EMR youngsters living at home who expect a change in living arrangement regard a move to an independent living situation as most likely for their youngsters, with 16% of parents of center-based completers and 39% of mainstream completers giving this response.

EXPECTED LIVING ARRANGEMENTS IN FIVE YEARS
Youngsters Now Living at Home

	TMR		Center EMR		Mainstream		Total	
Living Arrangement	#	(%)	#	(%)	#	(%)	#	(%)
Parent/Guardian	28	(76)	23	(61)	8	(44)	59	(63)
CLA, Group Home	6	(16)	1	(3)			7	(8)
Independent	1	(3)	6	(16)	7	(39)	14	(15)
With Sibling					1	(6)	1	(1)
Parent or Sibling					1	(6)	1	(1)
Don't know	2	(5)	8	(21)	1	(6)	11	(12)
Total	37	(100)	38	(100)	18	(100)	93	(100)

Whether parents have explored the possibility of youngster's living away from home: All parents and guardians whose mentally retarded youngster live at home with them were asked whether they had ever explored the possibility of her/her living away from home. For the total sample, including all exceptionality groups, 39 of the 106 parents whose youngster live at home (37%) had explored this possibility, 67 (63%) had not. Looking specifically at the TMR and EMR groups (see table next page), we see that 46% of parents of TMR youngsters at home, 32% of parents of center-based EMR youngsters at home, and 17% of parents of mainstream EMR youngsters at home had explored this possibility.

PARENTS/GUARDIANS WHO EXPLORED POSSIBILITY OF YOUNGSTER LIVING AWAY FROM HOME

	TMR		EMR		Mainstream		Total	
	#	(%)	#	(%)	#	(%)	#	(%)
Yes	17	(46)	12	(32)	3	(17)	32	(34)
No	20	(54)	26	(68)	15	(83)	61	(66)
Total	37	(100)	38	(100)	18	(100)	93	(100)

In order to investigate the factors related to consideration of youngsters' living away from home, the age of the parent was considered. In the table below the responses of parents in homes in which one of the parents is above 60 years old are compared with those of younger parents. Almost half of the older parents (48%) had explored the possibility of youngsters living away from home compared with 32% of younger parents. Although this distribution of responses was not found to be statistically significant, it may suggest that age of parent be further explored as a factor in this variable.

CONSIDERATION OF YOUNGSTER'S LIVING AWAY FROM HOME

By Age of Parent/Guardian

	Neither Parent Age 60 or Older		At Least 1 Parent Age 60 or Older		Total	
Explored Possiblity	#	(%)	#	(%)	#	(%)
Yes	23	(32)	16	(48)	39	(37)
No	50	(68)	17	(52)	67	(63)
Total	25	(100)	23	(100)	48	(100)

Steps taken: Those parents/guardians who indicated that they had explored the possibility of their youngsters' living away from home were asked what steps they had taken. Responses are presented in the table below. Parents gave multiple responses to this item. It may be seen that half had contacted counselors, 30% had been placed on waiting lists for facilities, and 25% had discussed the possible move with their youngster. 15% had discussed the potential move with family member, 15% had applied for placement and 13% had visited a facility.

STEPS TAKEN BY PARENTS/GUARDIANS WHO EXPLORED POSSIBILITY OF YOUNGSTER LIVING AWAY

	#	(%)
Contacted Counselor	20	(50)
Placed on Waiting List	12	(30)
Discussed with Youngster	10	(25)
Discussed with Family Members	6	(15)
Applied for Placement	6	(15)
Visited Facility	5	(13)

N = 40

Reasons why not living away from home: Parents who indicated they had explored the possibility of their youngster living away from home were asked why he/she was not living away from home at present. Answers are in the table on the next page. The most frequent answer, given by almost half the parents, was that they decided against it. Reasons given by parents for deciding against it include: satisfied with situation as it is, facility is an unsafe area, and potential loss of Social Security benefits if youngster left home. Other reasons why youngster were not living away from home were: on waiting list (22%), youngster did not want to (21%), no openings (10%), youngster had previously been away and had returned home (7%), and absence of suitable facilities (5%).

WHY YOUNGSTER IS NOT LIVING AWAY FROM HOME
Those Who Explored the Possibility

Reason Given	#	%
Parents decided against it	19	(49)
Currently on waiting list	9	(23)
Youngster did not want it	8	(21)
No openings	4	(10)
Youngster was away, returned home	3	(8)
Better off at home	3	(8)
No suitable facilities	2	(5)
Not financially feasible	1	(3)
Not financially eligible	1	(3)
Other	13	(33)

N = 39

Critical qualities of a CLA: Parents were asked the qualities that were important to them in a CLA or group apartment: what such an facility would have to have for them to be willing to consider it for their youngster. The most frequent response, cited by half the respondents, was good supervision. This appears to be especially important to parents of TMR (61%) and SPMR (63%) youngsters. Next most frequently mentioned by respondents was that the facility be close to home (12%). Singled out as the third most important quality, by 11% of respondents, was that it have opportunities for interaction with others; that social activities be provided. Parents of center-based EMR and TMR mentioned this quality. Characteristics of the staff were cited as important by 9% of the sample, e.g. that they be kind and intelligent, loving, caring, have discipline and patience. The same percent felt a homelike, congenial, family atmosphere to be important. 8% each mentioned privacy, security and safety, provision of work or workshop activity, and proximity to work as critical.

QUALITIES OF CLAs EXPRESSED AS DESIRABLE BY PARENTS/GUARDIANS

	MAINSTREAM (N=5) %	EMR (N=42) %	TMR (N=41) %	PH/SED (N=9) %	SPMR (N=8) %	TOTAL (N=105) %
Supervision	20	45	61	33	63	50
Close to home	-	10	15	11	25	12
Interaction	-	14	15	-	-	11
Staff	-	5	15	11	-	9
Homelike atmosphere	-	12	2	22	13	9
Privacy	-	7	5	22	13	8
Security/safety	20	10	5	-	13	8
Provide work activity	-	-	15	-	25	8
Close to work	20	10	7	-	-	8
Clean	-	5	5	-	-	4
Activities	-	2	7	-	-	4
Independence	-	5	2	-	13	4
Particular agency	-	-	2	22	-	3
Protection	-	2	5	-	-	3
Care for secondary disability	-	-	2	11	13	3
Religious affiliation	-	2	2	-	-	2
Location	-	2	2	-	-	2
Understanding	-	2	-	-	-	1
Structured	-	-	2	-	-	1
Other	20	17	12	11	-	13
None	80	29	20	22	13	26
Do not know	-	14	7	11	13	10

Circumstances under which parents would consider youngster living away from home: All parents and guardians whose youngsters live with them were asked, "Under what circumstances would you consider his/her living away from home?". The table below indicates responses to this. The three most frequent responses were: in event of parent's death (49%), should parents become infirm (25%), and if youngster wants to (13%). The fourth most frequent response was "under no circumstances" (9%). Other responses included if he/she got married (8%), if a desirable living alternative became available (5%) and if he/she could afford it (7%).

CIRCUMSTANCES UNDER WHICH PARENT/GUARDIAN WOULD CONSIDER YOUNGSTER LIVING AWAY FROM HOME

	#	(%)
In event of parents' death	39	(37)
Should parents become infirm	26	(25)
If youngster wants to	14	(13)
Under no circumstances	10	(9)
If youngster got married	9	(8)
If youngster could afford it	7	(7)
If desirable living alternative became available	5	(5)
If youngster learned to cope	3	(3)
If we found a place we liked	1	(1)
Behavior of youngster worsens	1	(1)
When youngster turns 21	1	(1)
Other	6	(6)
Do not know	6	(6)

(N=106)

Where youngster would live if these circumstances occurred: A related question asked all parents of youngsters living at home was where the youngster would be likely to go to live if these circumstances occurred; what the most likely living arrangement would be. The table below presents these finding for those parents who indicated that the circumstances of parent death or infirmity would lead them to consider their youngster's living away from home (50% of parents). Interestingly enough, the most frequent answer, of 42% of these parents, was sibling, followed by CLA (36%). Other responses included other relative (6%), residential institution (6%), independently (4%) and don't know (11%). (A number of parents gave more than one answer.) In terms of the two major exceptionality groups, parents of EMR youngsters were most likely to see their youngsters as living with siblings (63%) in the event of their own death or infirmity,

second as moving to a CLA or group home (16%), third as living with other relatives (11%), and living independently (6%). 16% did not know where their youngster would move in this eventuality. Parent of TMRs saw their youngsters as moving to a CLA or group home (46%), living with siblings (35%), and living in a residential institution (8%). 8% did not know where their youngster would be living in the event of their own infirmity or demise.

YOUNGSTER'S LIKELY LIVING ARRANGEMENT IN EVENT OF DEATH OR INFIRMITY OF PARENT/GUARDIAN

	EMR		TMR		PH/SED		SPMR		TOTAL	
Likely Living Arrangement	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)
Live with Sibling	12	(71)	9	(35)	1	(50)			22	(42)
Live with Other Relative	2	(12)	1	(4)					3	(6)
Live in CLA, Group Home	3	(18)	12	(46)	1	(50)	3	50	19	(36)
Live Independently	2	(12)							2	(4)
Live in Residential Institution			2	(8)			1	17	3	(6)
Other							1	17	1	(2)
Do not know	3	(18)	2	(8)	1	(50)			6	(11)
N =	19		26		2		6		53	

WORK SITUATION

Apart from living arrangement, the other major factor that shapes these youngsters' lives is their work-related activity. These youngsters are to be found in a variety of situations, along a continuum which varies by degree of vocational content. Therapeutic Activities Centers (TACs) typically keep youngsters occupied in pre-vocational activities, such as activities of daily living. Individuals with more severe disabilities tend to be enrolled in TACs. Work Activities Centers (WACs) are the next step on the continuum. Participants typically are involved in activities that involve rudimentary work skills such as assembling and packaging, and work at a pace that is less than 50% of that of an average worker. Sheltered workshops move individuals closer to real work. Participants earn wages for working on contracts that may involving assembling, counting, packaging, wrapping and such skills. They work at a pace that is at least 50% of that of an average worker and earn wages that usually depend on the number of items completed. Competitive work for our sample encompasses both regular and supported employment, a new initiative which provides supports to workers and is designed to ease handicapped individuals' entry into the world of work. A few individuals are in vocational training programs. In this narrative, the term activities center refers to both TACs and WACs. Work-related activity or work activity includes all the situations described above. An individual described as having no work activity, or idle, was involved in none of these activities at the time of interview.

SPMR: The work activity situation of the 20 SPMR youngsters in the sample are as shown in the table below. The majority (83%) are in activity centers, the remainder have no activity. Youngsters in no activity are primarily those living at home with parents or guardians. No change in work activity situation has been seen for SPMR youngsters in the course of the study; all SPMR individuals have been in the same activity situation since leaving school.

PRESENT SITUATION OF SPMRs

	1986 Cohort		1987 Cohort		Total	
	#	(%)	#	(%)	#	(%)
Activities Center	18	(95)	6	(60)	24	(83)
No Activity	1	(5)	4	(40)	5	(17)
Total	19	(100)	10	(100)	29	(100)

Total non-SPMR sample: The work activity situation of the remainder of the sample is presented in the table on the following page. The major activity categories for the total non-SPMR sample are competitive employment (32%), no activity (28%), activity center (20%) and sheltered workshop (15%). Looking across the exceptionality categories, it can be seen that the competitive employment category is almost exclusively the province of EMR individuals, that TMRs dominate the activity center category, and that those individuals primarily categorized as having an physical or emotional handicap, in addition to mental retardation, are most likely to be in no work-related activity.

PRESENT SITUATION OF NON-SPMRs

	EMR		TMR		PH/SED		Mainstream		Total	
	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)
Regular Job	24	(48)	2	(4)	1	(9)	15	(60)	42	(31)
Supported Work	2	(4)							2	(1)
Sheltered Workshop	6	(12)	9	(19)	4	(36)	1	(4)	20	(15)
Activities Center	3	(6)	23	(48)	1	(9)			27	(20)
Training			1	(2)					1	(1)
No Activity	11	(22)	13	(27)	5	(45)	9	(36)	38	(28)
Unknown	4	(8)							4	(3)
Total	50	(100)	48	(100)	11	(100)	25	(100)	134	(100)

EMRs: The majority of EMRs, 55%, are employed, either in competitive or in supportive employment. There is a substantial minority of EMRs, 27%, who are in no work-related activity. The remainder of this group are in sheltered workshops (9%) or activities centers (4%). Looking at the three cohorts, we see that a full 61% of the '86 cohort is competitively employed, with only four individuals who are idle (17%) and 3 in sheltered workshops and activities centers (13%). The work-related situations of the '87 cohort are more varied. Fewer individuals are employed (44%), in competitive or supported work situations, than in the other cohorts, and more are in sheltered workshops and activities centers (23%). Over a quarter are unemployed (26%). The work-related activity situation of the mainstream cohort falls almost exclusively into two categories, competitive employment (60%) and no activity (36%), with only one individual in a sheltered workshop (4%). This group has the highest percentage of unemployed individuals of the EMR cohorts.

PRESENT SITUATION OF EMRs

	1986 Cohort		1987 Cohort		Mainstream		Total	
	#	(%)	#	(%)	#	(%)	#	(%)
Competitive Employment	14	(61)	10	(37)	15	(60)	39	(52)
Supported Work			2	(7)			2	(3)
Sheltered Workshop	1	(4)	5	(19)	1	(4)	7	(9)
Activities Center	2	(9)	1	(4)			3	(4)
No Activity	4	(17)	7	(26)	9	(36)	20	(27)
Unknown	2	(9)	2	(7)			4	(5)
Total	23	(100)	27	(100)	25	(100)	75	(100)

TMRs: The most common work activity situation of TMRs is activities center, with almost half the sample (48%) involved in such centers. As shown in the table on the next page, over a quarter (27%) are in no work-related activity, 19% are in sheltered workshops, 2 (4%) are in competitive employment and 1 (2%) is in training. Looking at the two TMR cohorts, we see that a consistent 48% of each is in activities centers. There is somewhat greater variation in work situation of the '86 cohort, with almost a quarter (24%) in no activity, 16% in sheltered workshops, 8% in competitive employment and 4% in training. The '87 cohort is to be found in three work situations: activities centers (48%), no activity (30%) and sheltered workshop (22%).

PRESENT SITUATION OF TMRs

	1986 Cohort		1987 Cohort		Total	
	#	(%)	#	(%)	#	(%)
Competivite Employment	2	(8)			2	(4)
Sheltered Workshop	4	(16)	5	(22)	9	(19)
Activities Center	12	(48)	11	(48)	23	(48)
Training	1	(4)			1	(2)
No Activity	6	(24)	7	(30)	13	(27)
Total	25	(100)	23	(100)	48	(100)

Changes in work-related situation

The work situations of the sample are characterized by stability. Most individuals have been found to be in the same type work situation each year that they have been interviewed. Few have made changes in work situation since leaving school. The minor changes seen in work situation do not evidence real progress toward greater independence or competitive work. Changes seen are almost as likely to involve a move from work to idleness as to be in the opposite direction. This variable will be discussed in greater detail for EMR and TMR exceptionality groups below.

EMRs: No one in the '86 center cohort had a change in work situation over the past year. All 4 of the idle youngsters in this cohort have been idle for the 3 years since they left school. 8 of the 14 competitive workers have been working since leaving school; the remaining 6 have been working since last year. The 2 individuals in activities centers, and the 1 in a sheltered workshop have been in these placements since leaving school. The '87 center cohort has had some change in work situation in the past year. 8 of the 10 individuals presently competitively employed had been so for the past two years, 2 were in no job-related activity last year. 6 of the 7 presently idle individuals have had no job-related activity since leaving school; one was working last year. Of the 5 EMR youngsters presently in sheltered workshops, 2 have been there since leaving school, 2 were idle last year, and one was in an activities center. The individual in an activities center last year is currently in a sheltered workshop. (To sum the major changes in the '87 cohort: 2 idle started in sheltered workshops this year, 1 idle started working competitively and 1 who had been working is now unemployed.) Some changes in work situation are also evident in the mainstream cohort, although they tend to be in

opposite directions. 11 of 15 individuals competitively employed, and 5 of 9 who are idle have been in the same situation for 2 years. 4 who had jobs last year are now idle, 4 who were idle now have jobs and 1 who was idle is now in a sheltered workshop.

TMRs: The TMR groups are also characterized by great stability and some small changes. In the '86 cohort, those 6 individuals who are presently idle have been so since leaving school. Of 12 individuals in activities centers, 10 have been there since leaving school, 1 has been there since last year and one was idle last year. The 4 individuals in sheltered workshops and 2 in competitive work have been in these placements since leaving school. The only other change of situation for this cohort is one individual who was in an activities center last year and is now in training. The '87 cohort shows even fewer changes in work situation. Only one individual, who was idle last year and is now in an activities center, had a change in work-related activity over the year. The remaining individuals - 5 in sheltered workshops, 10 in activities centers and 7 idle - have been in the same work-related situations since leaving school.

COMPETITIVE EMPLOYMENT

Present employment:

44 of the 163 youngsters (27%) in the sample are employed in competitive or supported work. 91% of these competitively employed individuals are EMRs, both mainstream (34%) and center-based (57%). The additional 9% of the workers (4 individuals) are also from the centers. Two are classified as TMRs and two as SED/LAP.

EXCEPTIONALITY OF WORKERS IN 1989

Exceptionality	#	(%)
Mainstream	15	(34)
Center:		
EMR	25	(57)
SED/LAP	2	(5)
TMR	2	(5)
Total	44	(100)

Types of Jobs: As the table below indicates, restaurants, including fast food enterprises, continue to be an important source of employment. Of the 44 subjects with jobs, 14 (32%) are working in restaurants or fast food outlets. Another 10 (23%) work in health care institutions, such as nursing home or hospitals. This group represents a growing sector of employment for the MR youngsters in the study: of the 10 employed in these institutions, 6 obtained their jobs since last year's follow-up study was conducted. At that time, all six were attending or had just completed training programs.

TYPES OF JOBS HELD BY THOSE WITH COMPETITIVE EMPLOYMENT

	Mainstream		Center		Total	
TYPES OF JOBS	#	(%)	#	(%)	#	(%)
Restaurant/food service:	5	(33)	10	(34)	15	(34)
Dishwasher	2	(13)	2	(7)	4	(9)
Busboy	2	(13)	1	(3)	3	(7)
Busboy/dishwasher			1	(3)	1	(2)
Porter			1	(3)	1	(2)
Misc. Restaurant	1	(7)	5	(17)	6	(14)
Nursing Home/Hospital:	4	(27)	6	(21)	10	(23)
Nurse Aide	1	(7)	5	(17)	6	(14)
Janitor			1	(3)	1	(2)
Laundry worker	1	(7)			1	(2)
Janitor/dishwasher	1	(7)			1	(2)
Snack shop worker	1	(7)			1	(2)
Other:						
Janitor			5	(17)	5	(11)
Warehouse caller			1	(3)	1	(2)
Navy			1	(3)	1	(2)
Bagger			1	(3)	1	(2)
Messenger	1	(7)			1	(2)
Meatcutter			1	(3)	1	(2)
Laborer	2	(13)	2	(7)	4	(9)
Stock clerk	1	(7)			1	(2)
Mechanic			1	(3)	1	(2)
Driver	1	(7)			1	(2)
Unknown	1	(7)	1	(3)	2	(5)
Total	15	(100)	29	(100)	44	(100)

Hours: Over half (52%) of those with a job are working full-time (at least 35 hours per week). 11/15 mainstream workers (73%) are working full-time, and only 1 (7%) is working less than 20 hours a week. 12/29 center youngsters (42%) are working full-time, 6 (21%) are working less than 20 hours a week. The individuals in the sample who are competitively employed work an average of 31.9 hours a week.

HOURS WORKED BY THOSE WITH COMPETITIVE EMPLOYMENT

	Mainstream		Center		Total	
	#	(%)	#	(%)	#	(%)
Less than 20	1	(7)	6	(21)	7	(16)
20 - 34	3	(20)	8	(28)	11	(25)
35 - 40	9	(60)	11	(38)	20	(45)
Over 40	2	(13)	1	(3)	3	(7)
Not known			3	(10)	3	(7)
Total	15	(100)	29	(100)	44	(100)
Average hours:	36.6		29.3		31.9	

Hourly wage: The average hourly wage of the workers is $4.12/hr. 7 workers (16%), 5 from center-based and 2 from mainstream cohorts, have earnings at or below the minimum wage of $3.35/hr. 6 individuals (14%) earn $5.00/hr or more.

HOURLY WAGES OF THOSE WITH COMPETITIVE EMPLOYMENT

	Mainstream	(%)	Center	(%)	Total	(%)
Less than $3.35			1	(3)	1	(2)
$3.35 (min. wage)	2	(13)	4	(14)	6	(14)
$3.65 - $3.85	2	(13)	6	(21)	8	(18)
$4.00 - $4.50	7	(47)	8	(28)	15	(34)
$5.00+	3	(20)	3	(10)	6	(14)
Not known	1	(7)	7	(24)	7	(16)
Total	15	(100)	29	(100)	44	(100)
Average hourly wage:	$4.20		$4.07		$4.12	

Weekly earnings: The average weekly earnings of the sample is $137.97. This is exactly 120% of 1989 poverty figures for individuals living alone, and so, represents a fairly limited income. There are, however, individuals, notably among the mainstream cohort, whose incomes are considerably above that level, largely because they are working longer hours. 23% of workers make under $100 a week.

WEEKLY WAGES OF WORKERS

	Mainstream	(%)	Center	(%)	Total	(%)
Less than $100	3	(20)	7	(24)	10	(23)
$100 - $149	3	(20)	7	(24)	10	(23)
$150 - $199	5	(33)	5	(17)	10	(23)
$200+	3	(20)	3	(10)	6	(14)
Not known	1	(7)	7	(24)	8	(18)
Total	15	(100)	29	(100)	44	(100)
Average weekly wages:	$161.01		$122.62		$137.97	

Job referral: The workers obtained their jobs through family or friend contacts (25%), youngster's inquiry (20%), training programs (18%), in-school coop job placements (18%) and through training program placements (18%). Center and mainstream workers appear to differ on this variable, with center youngsters relying more on institutional contacts, and mainstream youngsters on informal sources. 59% of the center workers obtained their jobs through institutional contacts: 6 through training programs, 3 through agencies such as VRC, OVR and CEO, and 8 turned in-school co-op placements into permanent jobs. 41% of the center workers found jobs though informal sources - family and friends, and their own inquiries. 20% of the mainstream workers were referred through agencies or programs, 54% obtained their jobs by applying in person or through family and friend contacts.

SOURCES OF JOB REFERRAL

Job referral	Mainstream	(%)	Center	(%)	Total	(%)
Training Program	2	(13)	6	(21)	8	(18)
Agency	1	(7)	3	(10)	4	(9)
In-school Co-op			8	(28)	8	(18)
Family/friend	4	(27)	7	(24)	11	(25)
Youngster's inquiry	4	(27)	5	(17)	9	(20)
Not known	4	(27)			4	(9)
Total	15	(100)	29	(100)	44	(100)

Transportation to work: 73% of the workers get to their jobs independently by using public transit, walking, or driving themselves. 20% ride with a friend or relative. Mainstream workers are especially self-reliant; with 93% getting to work independently and only 1 (7%) getting a ride.

MEANS OF TRANSPORTATION TO WORK

	Mainstream	(%)	Center	(%)	Total	(%)
Gets Ride	1	(7)	8	(28)	9	(20)
Public Transit	2	(13)	8	(28)	10	(23)
Walks	5	(33)	4	(14)	9	(20)
Bicycle			1	(3)	1	(2)
Drives Self	5	(33)	7	(24)	12	(27)
Not known	2	(13)	1	(3)	3	(7)
Total	15	(100)	29	(100)	44	(100)

Improvement in wages or hours: 25 of the workers are working in the same job they held at last year's follow-up study. 15 of these (60%) have experienced increases in hourly wages and/or hours worked. The proportion is somewhat smaller for center workers (55%) than for mainstreamers (71%).

IMPROVEMENT IN WAGES OR HOURS

	Mainstream	(%)	Center	(%)	Total	(%)
Increase in wages and/or hours	5	(71)	10	(55)	15	(60)
No increase in wages and/or hours	2	(29)	8	(45)	10	(40)
Total	7	(100)	18	(100)	25	(100)

TRAINING AND PLACEMENT

In last year's study it was discovered that several youngsters were enrolled, or had just completed, formal training programs aimed toward eventual placement in a specific occupation or work setting. Since then, many of these youngsters have found employment related to the subject area of the training. This section reviews the types of training undertaken by the youngsters and the outcome of that training.

Post-school training: Seventeen youngsters have completed post-school training programs since leaving school. 12 of these (71%) are center completers, while the remaining 5 (29%) were mainstreamed.

EXCEPTIONALITY OF YOUNGSTERS WITH POST-SCHOOL TRAINING

Exceptionality	#	(%)
Mainstream	5	(29)
Center:		
EMR	10	(59)
SED/LAP	2	(12)
Total	17	(100)

Type of training: As the table below shows, the most popular training programs for our study subjects were Nurse's Aide (35%), Janitor/Custodian (24%) and Food Service (18%). Other fields studied were food service, commercial art, machinist, cooking and business.

Training Subject	#	(%)
Nurse Aide	6	(35)
Janitor/Custodian	4	(24)
Food Service	3	(18)
Commercial Art	1	(6)
Machinist	1	(6)
Cooking	1	(6)
Business	1	(6)
Total	17	(100)

Mainstream and center trainees were enrolled as follows:

	Mainstream	Center
Food Service	2	1
Nurse Aide	1	5
Janitorial	-	4
Commercial Art	-	1
Machinist	-	1
Cooking	1	-
Business	1	-
Total	5	12

Jobs in field of training: As the table below shows, 14 of the 17 trainees (82%) obtained a job after completion of their training. 10 of the 14 (71%) obtained jobs in the fields in which they were trained. 2 others found employment in related work settings, but are doing different work than that for which they trained (i.e., a food service trainee working as a dishwasher, a nurse aide trainee working as a janitor in a nursing home). Of the 3 who are not now working, 2 (a janitor and a machinist) had obtained jobs in their fields but lost them; the third has just completed training as a cook and is presently job-hunting.

Training Subject	Idle	With Job: Not in Field	With Job: In Field	Total Trainees
Nurse Aide		1	5	6
Janitorial	1		3	4
Food Service		1	2	3
Machinist	1			1
Cooking	1			1
Commercial Art		1		1
Business		1		1
	3	4	10	17

Center Completers: The Importance of Training

Training has been an important steppingstone to employment for many center completers. As the table below shows, 83% of those center EMRs and SED/LAPs who received post-school vocational training had jobs, compared with 38% of those who did not have such training. Those who received post-school training were more likely to be employed than those who had not received such training (p=.013).

EMPLOYMENT STATUS BY POST-SCHOOL TRAINING
Center Completers, EMR and SED/LAP

	No Post-school Training		With Post-school Training		Total	
	#	(%)	#	(%)	#	(%)
Without a job	28	(62)	2	(17)	30	(53)
With a job	17	(38)	10	(83)	27	(47)
Total	45	(100)	12	(100)	57	(100)

$X^2 = 6.16$, p.=.013

IDLE YOUNGSTERS

Youngsters who are not involved in any work- or training-related activity are classified as idle in the study. In this year's non-SPMR sample, 38 individuals, 28% of the sample, are idle. These individuals are:

Mainstream	9	(36% of total mainstream)
Center EMR	11	(22% of total Center EMR)
TMR	13	(27% of total TMR)
PH/SED	5	(45% of total PH/SED)
	38	(28% of total non-SPMR sample)

A large proportion of these individuals might be called the hard-core idle of this research. 31 out of the 38 currently idle, 82%, have been idle each time they have been contacted by the study. The majority have had no work or training involvement since leaving school. Some, notably a number of the mainstream and center EMRs, have been involved in work-related activities which did not last. Each yearly interview, therefore, found them uninvolved in work.

We were interested in exploring the situation of idle youngsters in greater detail. Why weren't they involved in some vocationally-oriented activity? What did they do with themselves? Parents, therefore, were asked, "Why do you feel he/she is not working at present?" and "What does he/she do on an average day? In which activities does he/she spend the most time?" Parents of youngsters who had had some job experience were also asked, "Why did he/she leave his/her last job?" Findings from these variables,for all idle youngsters from all exceptionality groups, are presented in the tables below.

Reason for leaving last job: The major reason for leaving previous job, for 31% of this group, was "could not handle work". Other reasons include dissatisfied with an aspect of work, such as hours or conditions (15%), dismissed (15%), and program/job ended or terminated (15%). These results are shown in the table on the following page.

WHY YOUNGSTER LEFT PREVIOUS JOB

Reason given	#	%
Could not handle work	4	(31)
Dissatisfied with aspect of work	2	(15)
Dismissed	2	(15)
Transportation problems	1	(8)
Program/job ended or terminated	2	(15)
Family prefers he/she not work	1	(8)
Employer's attitude	1	(8)
Quit	1	(8)
Can't stay out of trouble	1	(8)
Car accident-injured	1	(8)

N = 13

Reason why not working at present: As viewed by the parent or guardian, the reason that a youngster is not working now is most often that he/she cannot handle the work situation, that his/her disability prevents employment, or that his/her skills or ability are not sufficient for work (39%). 56% of parents of idle TMRs cited such reasons . Youngster's attitude was also pointed out as a major deterrent to employment, by 16% of parents or guardians. Work not being available or being on waiting lists, and have not pursued work were each cited as reasons by 13% of respondents. Other reasons given include: transportation problems (10%), pregnancy/marriage/family (6%), cannot find suitable job or niche (6%) employer attitude (3%), drinking problem (3%) and no facilities in the area (3%). These results are shown on the table on the following page.

REASONS GIVEN FOR WHY YOUNGSTER IS NOT IN WORK SITUATION

	MAINSTREAM (N=8)		EMR (N=10)		TMR (N=9)		PH/SED (N=2)		TOTAL (N=132)	
	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)
Cannot handle work situation, disability prevents employment	3	(38)	3	(30)	5	(56)	1	(50)	12	(39)
Youngster's attitude, behavior	1	(13)	2	(20)	2	(22)			5	(16)
Can't get in program - waiting list, applied for job, not called			1	(10)	3	(33)			4	(13)
Has not pursued work			3	(30)					3	(10)
Transportation problems	1	(13)	1	(10)			1	(50)	3	(10)
Pregnancy-marriage-family	1	(13)	1	(10)					2	(6)
Can not find suitable work	1	(13)					1	(50)	2	(6)
Problem with system	1	(13)							1	(3)
Family prefers he/she not work					1	(11)			1	(3)
Drinking problem			1	(10)					1	(3)
Employers' attitude			1	(10)					1	(3)
Health problems					1	(11)			1	(3)
No facilities in the area	1	(13)							1	(3)

How the idle spend their time: We were interested in learning how youngsters who are not involved in any vocationally-oriented activity spend their time. The two most common activities mentioned by respondents are helping around the house, doing chores and running errands, in which half these youngsters participate; and watching television (28%). The next most frequent activities, each carried out by 19% of the idle youngsters, are: home-based activities like reading, drawing and listening to music; shopping; and walking or exercise. 16% of these youngsters were described as "hanging around". 6% each spends some of their time job-hunting, sleeping, in volunteer work, caring for their baby, or sitting around. Particular exceptionality groups were involved in somewhat different patterns of activity. Mainstream youngsters' most frequent activities were television (57%), helping with chores (29%), and caring for their babies (29%). Half of the idle center-based EMRs were described as helping with chores and a quarter each as reading, drawing and listening to music, and as hanging around. 90% of idle TMRs helped with chores, and 40% each shopped, and exercised or walked. Half of the 4 idle PH/SED youngsters spend their time watching television and hanging around.

DAILY ACTIVITIES OF YOUNGSTERS WHO ARE NOT IN A WORK SITUATION

	MAINSTREAM (N=7)	EMR (N=8)	TMR (N=10)	PH/SED (N=4)	SPMR (N=3)	TOTAL (N=32)
	%	%	%	%	%	%
Helping with chores, errands	29	50	90	25	-	50
Watching television	57	-	20	50	33	28
Reading, drawing, listening to music	14	25	20	25	-	19
Shopping	14	-	40	25	-	19
Walking, exercise, sports	14	13	40	-	-	19
Hanging around	-	25	10	50	-	16
Job-hunting	14	13	-	-	-	6
Sleeping	14	13	-	-	-	6
Volunteer work	-	13	-	25	-	6
Caring for baby	29	-	-	-	-	6
Sitting around	-	-	10	25	-	6
Fixing bicycles	-	13	-	-	-	3
Sexually active	-	-	-	25	-	3
Other	-	-	10	25	100	16
Do not know	14	13	-	-	-	6

PARENT CONCERNS AND DESIRED HELP FROM HUMAN SERVICES

We were interested in determining parents' and guardians' perceptions of their and their retarded youngsters' lives. In order to use these perceptions as a basis for policy planning, we asked parents to tell us their greatest areas of concern in terms of their youngster's life and future, and to describe the help from the human services system that would be useful to them in dealing with these concerns. Interviewers were instructed to do as little prompting as possible on these items, to allow parents to share their concerns with us in their own words. We, thus, have obtained a rich pool of parent-based material for use in policy analysis and service planning.

Areas of greatest concern: The table on the following page presents the findings on this variable. Parents were asked to indicate their three greatest areas of concern in respect to their children's life and future. Parents of youngsters in particular exceptionality groups can be seen to have somewhat different concerns. The largest percent of parents, 30% of the total sample, see work-related issues as their greatest concern for their children. Work and vocational training is the parent's greatest area of concern for their children. Some voiced specific concerns such as "he doesn't know what he wants to do", "I'm concerned that he keep his job", and "I want him to have something to do, some activity". Parents of both EMR groups, mainstream (32%) and center (38%), and the TMR group (29%), were most apt to see this as an area of concern. Next most frequently voiced by respondents was a concern for their own infirmity or death, presumably because this would leave their youngster without a caregiver. 29% of the total sample cited concerns in this area. Higher percentages of parents of more severely handicapped youngsters - TMR (43%), PH/SED (33%) and notably SPMR (56%) - noted this as a concern. Physical health of their youngster was the third most frequently noted concern of the total sample, cited by 17% of respondents. Understandably, larger proportions of parents of PH/SED (44%) and TMR (29%) youngsters view this as a concern. Next most frequently noted areas of concern by parents were: housing and living arrangement (14%), social life and social skills (12%), finances and financial self-sufficiency (12%), and generally coping with life and taking care of oneself (12%). Parents of more handicapped youngsters also felt guardianship to be an area of concern; 14% parents of TMR youngsters and 22% of those of SPMR youngsters mentioned this. Youngsters' personality and personal characteristics were a concern of 16% of parents of mainstream EMRs and 11% of parents of PH/SEDs. Respondents voiced comments like "he introverts on problems", "he becomes confused and angry if there's too much pressure", and "he needs a better sense of

CONCERNS FOR YOUNGSTER'S FUTURE EXPRESSED BY PARENT OR GUARDIAN

Percent of Responses by Exceptionality of Youngster

	MAINSTREAM (N=25) %	EMR (N=47) %	TMR (N=42) %	PH/SED (N=9) %	SPMR (N=9) %	TOTAL (N=132) %
Work/voc.training/work-related problems	32	38	29	11	-	30
Infirmity/death of caregiver	8	21	43	33	56	29
Physical health of youngster	-	9	29	44	22	17
Housing, living arrangement	-	19	17	11	11	14
Social life, social skills	12	19	7	-	11	12
Finances	16	17	5	22	-	12
Coping, taking care of himself	-	17	10	22	22	12
Guardianship, someone to take care of him	4	6	14	11	22	10
Personal characteristics, (e.g, temper, forgetfulness)	16	4	2	11	-	6
Education - reading, cooking	8	6	7	-	-	6
Marriage, marriage counseling	4	11	-	-	-	5
Safety	-	-	7	-	-	2
Transportation	-	2	2	-	-	2
Medical insurance	8	-	-	-	-	2
Medical care	4	-	-	11	-	2
Possible involvement with sex, drugs	-	2	-	-	-	1
Mental health	-	2	-	-	-	1
Cutbacks in MR programming	-	-	2	-	-	1
Don't know	4	2	-	-	-	2
Other	4	-	-	11	-	2
None	-	2	-	-	-	1

self-worth". **Problems related to marriage** - concern for the future of a daughter's marriage, feeling that marriage counseling was needed - were cited by 11% of parents of center-based EMRs.

Desired help from human services: Given the varied concerns for their youngsters that they voiced, parents did not look to the human service system as a potential source of help in many areas. Only a few types of social service programs were cited as desireable by considerable numbers of parents. Most strongly voiced was a desire for additional **work and training opportunities** for their handicapped youngsters. Also mentioned in this regard were "programming when school leaves off", "more workshop programs", and "better, earlier planning for transition". 38% of the total sample would like such help. The desire for such assistance was especially noted by mainstream (48%) and center EMR (40%) parents, and also by those with PH/SED children (56%). The next most frequently requested area of social service programming was **social and recreational programs** for youngsters. 17% of the total sample felt the development of such programming to be desirable. Third most frequently cited by parents was **additional education in basic life areas** for their children. 12% of the total sample would like to see additional opportunities for their children to be trained in such areas as mobility, cooking, and banking. Additional help from social services desired by particular parent groups include **respite care**, cited by parents of more handicapped youngsters, SPMR (22%) and TMR (14%); and **housing opportunities and residential facilities**, indicated by parents of SPMR (22%) and PH/SED (21%) youngsters. 22% of parents indicated that they needed **no help** from the human services system.

SERVICES PARENTS AND GUARDIANS FEEL WOULD BE MOST USEFUL IN ADDRESSING THEIR CONCERNS

Percent of Responses by Exceptionality of Youngster

	MAINSTREAM (N=25) %	EMR (N=48) %	TMR (N=42) %	PH/SED (N=9) %	SPMR (N=9) %	TOTAL (N=133) %
Work/training/post-school programming	48	40	29	56	22	38
Social/recreational programs	12	17	17	22	22	17
Self-help, mobility training	12	15	10	11	11	12
Counseling, support groups	-	13	7	11	11	8
Respite care	-	4	14	11	22	8
Modification of SSI benefits	8	8	7	-	11	8
Housing opportunities	-	4	2	11	44	6
Financial assistance, counseling	8	6	7	-	-	6
Medical care, insurance	4	6	5	-	-	5
Transportation	-	6	7	-	-	5
Contact person	4	2	-	-	-	2
In-home help	-	-	2	-	11	2
Public acceptance	-	-	2	-	-	1
Other	-	6	12	33	-	8
Don't know	8	2	-	-	-	2
No help needed	32	15	29	-	22	22

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